

The Needs Of Well Spouses Of People With Kidney Failure: A Case Study

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Abstract

This case study was prepared by a psychotherapist who was married for 29 years to a kidney failure patient. Private caregivers for the chronically ill are not the patient and they tend to be neglected by caregiving professionals. They have special problems that affect their health and the quality of their life, the fullness of their personal relationship to the ill person, life choices such as adoption, and whether or not to terminate or limit their caregiving relationship. A powerful influence on the caregiver is metaphor, chosen consciously or unconsciously, concerning the nature of life and of their relationship. Professional caregivers should be aware of the potential conflict of interest that may exist between caregivers and their chronically ill loved ones. This article provides many practical solutions for the care of caregivers by doctors, nurses and mental health professionals.

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The undercurrent of chronic illness is like the volcano: it does not go away. It menaces. It erupts. One damned thing follows another. –Arthur Kleinman, M.D. (1988)

Once you [the support person] decide you have to talk, the problem is to whom? The loved one is probably not the best person to discuss some of your problems with, simply because they often are your problem. . . . –Ken Wilber (2000)

I do know I'll never walk down the street with my man, feeling part of an ordinary couple. I'll be holding [my husband's] . . . hand to support him, or pushing his chair. –Maggie Strong (1988)

If you live facing the challenge of chronic illness in your life or in the life of someone you love, you have no choice but to master the dance. Once you put on your dancing shoes, find the proper music, create the appropriate atmosphere, you will lead your chronic illness, your partner, onto the dance floor like a world-champion dancer, with dignity and grace. –Louise Giroux (1998)

INTRODUCTION

There are roughly five to eight million well spouses of

chronically ill people in the United States alone (see Strong, 1988). The strain of caregiving may seriously affect the health of these caregivers (Haug, 1999).

The incidence of diseases may be estimated somewhat more precisely. By one account, "14 percent of all Americans are limited in their activities by a chronic medical condition" (McDaniel Hepworth and Doherty, 1992). This includes people afflicted by dementia (Alzheimer's syndrome, vascular dementia and other causes), cancer, multiple sclerosis, serious mental illness (including substance dependence and PTSD), Crohn's disease, congenital birth defects and retardation, and AIDS (Lindqvist, Carlsson and Sjoden, 2000). Kidney failure affects about 200,000 people in the United States, or four out of every 10,000 people (Cameron, 1996).

This article reflects my personal experience of 29 years of marriage to a spouse with kidney failure. My wife and I experienced the effects of two kinds of dialysis and of kidney transplantation. We had many warm and loving times, including some in the midst of health traumas, and there were other times of frustration, fear and despair. My wife demonstrated great courage, perseverance and love in the face of overwhelming setbacks. By living with her, I became a more compassionate, caring person.. Shortly before she died, I left her.

Caregivers are entitled to respect for their own personal

suffering (McDaniel 1992; McDaniel, Hepworth and Doherty, 1995; Strong, 1988; Wilber, 2000). The well spouse, with support from the ill partner, can seek an equal relationship in which each supports the other through times of suffering. It should not be assumed that the interests of the well spouse should be subordinated to that of the patient or that they are identical to that of the patient (Strong, 1988). It also should not be assumed that the ill person is too weak to provide support for her well partner (but see Wilber, 2000). If she is, then the support person may find it necessary to rely on a support group or on psycho-therapy (Wilber, 2000).

It is all too easy for both a kidney failure patient and a well spouse to be noble victims, willingly accepting their suffering as Christ accepted his crucifixion. This metaphor is limiting. It severely restricts the ability to embrace and enjoy life (Dreikurs, 1997), to enhance the quality of a marital relationship and to make sound decisions, including whether to adopt a child. As Rudolf Dreikurs (1997) wrote, “[W]e are all the masters of our fate to an unbelievable degree, but we feel and act as if we were the victims of circumstances beyond our control.” To live their lives fully and successfully, the chronically ill and their well spouses might choose another, more life-sustaining metaphor than the “willing suffering” or martyrdom (Dreikurs, 1997). One powerful metaphor -- dancing with chronic illness -- has been suggested by a person who dances with multiple sclerosis (Giroux, 1998).

The patient, the well spouse and their therapist should be aware of the important place that metaphor plays in the quality of life. As Kopp (1995) has written:

Metaphor carries meaning over from one domain to another. When Romeo declares, “Juliet is the sun,” for example, the sun's qualities convey the meaning that is “carried over” to Juliet.

Metaphors suggest the existence of imaginative-cognitive processes, which combine the mental processes that characterize both the left and right sides of the brain (Kopp, 1995). By working with and modifying metaphors, new patterns and connections can be established and a client may be encouraged to take an entirely new approach to existing life circumstances. In the context of chronic illness, metaphor work is promising because it may powerfully affect the quality of life (Kopp, 1995). As trauma follows trauma, the quality of life can continue to be improved. The extent to which metaphors can cope with the descending

ladder of disease is as yet uncertain because there are no data about the consistent use of this method of therapy.

Chronic disease may also be thought of as necessitating grief concerning losses that have occurred or are clearly foreseeable. The well spouse and the patient both experience enormous loss as the result of the chronic illness and its complications, and it may well be necessary for both to grieve this loss in order to go beyond the sadness, anger and fear that may at first engulf them (Giroux, 1998; Strong, 1988). After they grieve, they may be freer to determine the direction in which each is going to move (Dreikurs, 1997).

Whether or not a couple is coping well with a chronic illness requires a complex, sensitive clinical judgment. It is common even among healthy people for them to justify themselves and to ignore the possibility of further enriching their lives, so a therapist cannot necessarily count on the client to know what changes are possible (Ehrlich, 2000; Scott, 2000). (See Strong, 1988, who assumes that her husband could not face some personal truths that she withheld from him; Wilber, 2000; but see Scott, 2000.)

A professional caregiver may wonder, in light of the patient's known physical ailments, how well a patient and well spouse are coping with difficulties. Are they unnecessarily avoiding interpersonal or sexual contact? Are they communicating well (Ehrlich, 2000)? Are they cooperating with their doctors in effective care of the patient? Are they hurting the quality of their life by abusing substances (Giroux, 1998)? Are they appropriately involved in socially useful and personally satisfying activities (Dreikurs, 1997; Wilbur 2000)? Are they using metaphors that support the quality of their lives (Kopp, 1995)? Are they being real (Scott, 2000)? These important questions, whose answers may be elusive, can be pursued with the affected couple by the primary care physician, a capable nurse or a psychotherapist. Then, if appropriate, referrals can be made for group, couples, family or individual psychotherapy or for a caregiver support group (Strong, 1988; Well-Spouse Foundation, 1992; Wilbur 2000).

Professional caregivers should guard against overprotecting their patient by understating the seriousness of their condition. Whether or not this lack of truth may at times be justified for avoiding harmful effects on the ill person, it is very likely to have harmful effects on those who care for them.

A purpose of this article is to improve the care given by

health care professionals to all well spouses and caregivers, particularly those coping with End Stage Renal Disease (ESRD), more commonly called “kidney failure.” The article intersperses citations to the existing literature with personal insights and reflections about caring for my late wife during her chronic kidney failure.

LITERATURE REVIEW

For the most part, the caregiver of the chronically ill has been a forgotten person. One exception to this rule is a superb book written in 1988 by Maggie Strong, *Mainstay: For the Well Spouse of the Chronically Ill*. In her book, Strong provides a sensitive account of her marriage to a husband who suffered from multiple sclerosis. In addition, Strong founded the Well Spouse Foundation (<http://www.wellspouse.org/information.html>), which runs support groups for well spouses.

Another bright spot in the literature is Louise Giroux's book, *Taking the lead: Dancing with Chronic Illness* (1998). She intersperses her story of her struggle with multiple sclerosis with comments sensitive to the needs of caregivers. A third, superbly sensitive, spiritually alive and emotionally balanced chronicle is Ken Wilbur, *Grace and grit: Spirituality and healing in the life and death of Treya Killam Wilber* (2000).

Generally speaking, the focus in the existing literature is on the patient and the independent needs of the well spouse are ignored or minimized (McDaniel, Hepworth and Doherty, 1992). Although there have been useful studies of the coping mechanisms used by the spouses of kidney failure patients (Lindqvist, Carlsson and Sjoden, 2000), these studies are single frames taken from a long, often depressing movie. The literature also includes stories of chronic illnesses. One involves a patient suffering kidney failure associated with diabetes mellitus and hypertension. In that article, there is intensive analysis of the relationship of health professionals to the patient and her spouse but the spouse viewed as a caregiver and is not considered as a separate individual (Swartz and Prochaska, 1998). Similarly, Kleinman (1988) sees the importance of the patient's response to the chronic disease, but he does not offer special assistance to caregivers. Kleinman states:

Chronic illness places the family under substantial, ongoing pressure that exacerbates existing conflicts while it creates new ones. The practitioner may come to see the entire family as the focus of care. He will want to determine specific problems in its functioning and respond, where appropriate, to them.. The response should include regular assessment

and follow-up of the family's problems along with counseling and, if necessary, referral to family therapy specialists.

There is growing awareness of the importance of holistic treatment for the chronically ill, but there is far less awareness of the independent needs of spouses, relatives or other regular caregivers (Doherty & Macaran 1983; Dreikurs (deceased) 1997; Kleinman, 1988; McDaniel, Hepworth and Doherty, 1992). The emphasis in these sources is on families and, with the exception of McDaniel, Hepworth and Doherty (1992), the special needs of caregivers are generally not recognized. By ignoring the needs of a spouse, the literature may even inadvertently increase the already substantial risk (Giroux, 1998; Strong, 1988) that family breakup may occur.

That there are now a few sources acknowledging the specific needs of caregivers, indicates that a new phase of awareness may be beginning. The Life Options Rehabilitations Advisory Council and the American Association of Kidney Patients or AAKP (2000) and Phillips (1987) provide substantial assistance to the spouses of kidney failure patients. The Life Options Rehabilitation Advisory Council and the AAKP provide many useful insights, including a thoughtful chapter on, “Building on Your Relationship.” They state that, “If your relationship was healthy before dialysis, it still can be. . . . Nothing is more important than a loving relationship, which can be preserved and grown, even with kidney failure.” Phillips provides helpful advice about living with someone with kidney failure and about how a kidney failure patient may improve family interactions and learn to cope with difficult emotions. However, both of these sources are developed from the standpoint of the patient.

The Life Options Rehabilitation Advisory Council and the AAKP (2000) surface various important life issues, including some very difficult feelings that caregiver-spouses may experience. It does not recognize, as Strong (1988) does, that the well spouse has one option the ill spouse does not have: to be relieved of the continuous blows dealt by the sick spouse's illness by leaving the relationship. It also does not recognize that caregivers may need to seek separate psychotherapy or group support to find a constructive resolution that is suited to their particular interests.

In the area of sexual compatibility, The Life Options Rehabilitation Advisory Council and the AAKP (2000) acknowledge that chronic illness may affect a couple's sex life. Dr. David Schnarch also addresses this problem, stressing that couples who are “fused” may need to become

more individualized or differentiated in order to improve their relationship and their sexuality (Schnarch, 1998).

Unless a couple undertakes serious work on their relationship, they will never discern whether their couple problems are psychological – due to their metaphors and misunderstandings – or physiological.

In addition, as Strong (1988) and Wilbur (2000) I have observed, it is important for a well spouse to develop independent spiritual resources and interests, including activities outside of the home and activities separate from patient (The Life Options Rehabilitation Advisory Council and AAKP, 2000). I found meditation to be a particularly useful spiritual practice (<http://www.meditatenow.com>) and I also took comfort from prayer and the worship of Jesus Christ (Bloch, 1997, <http://www.meditatenow.com/tab1cont.htm>).

There appear to be two principal reasons why the needs of caregivers may sometimes be overlooked. One reason may be deduced from the first sentence of an article by Ann Burack-Weiss (1995), who states, “A commitment to families is the hallmark of the social work profession, and the emphasis is nowhere more evident than in the intervention of enhancing informal supports in cases of illness and disability.” [Emphasis added.] That statement, also endorsed by some family physicians (Doherty & Macaran, 1983), implies that the client is the kidney failure patient and that the caregiver is support. I infer that another reason that the needs of caregivers are not fully appreciated, is greater empathy for the patient and the likelihood that the caregiver may not represent or understand their own best interest because of guilt about the greater suffering of the patient.

The well spouse and the patient make the physician's job harder because they often cope through harmful denial, also called “optimism” (Lindqvst, Carlsson and Sjoden, 2000). For example, my spouse and I implicitly decided, early in her illness, that I would not express my emotional reactions to her physical deterioration, permitting her to “deny” the impact of her disease on me (see Strong, 1988). My spouse tried always to do her best with her illness, but she acknowledged that she needed support. I took the role of the strong supporter. When I once broke this unspoken rule by mentioning that I felt a heavy weight on my chest when I approached our home, my spouse responded that she was happy during the same time period in which I felt distress. In this way, the importance of my feelings was dismissed, much in the same spirit as Strong's pain was dismissed by

her husband's remark that, “He hurt more.” (Strong, 1988).

PROFESSIONALS MAY MISLEAD CAREGIVERS AND PROVIDE INCOMPLETE INFORMATION

During my late wife's lengthy illness, there were times when doctors provided incomplete information or told us less than they knew -- though there were times when they also knew less than we wanted them to know. They may have failed to reveal some things because they had many patients with complex illnesses and felt that they did not have the time to explain things fully. They also may have remained vague in part because they wanted to spare their patient additional mental pain related to an uncertain future. However, the result was poor information about her illness (Lindqvst, Carlsson and Sjoden, 2000). For example, before we were married a doctor misled us by reassuring us (without a sound basis) that she probably would not have serious consequences from her glomerulonephritis until she was 80. Later on, poor information was given about the effects her illness might make have on her ability to care properly for an adopted child. And in the last year of my wife's final illness, doctors responded to specific medical concerns but not to honest fears that my wife was dying.

These omissions, while important to me, do not seriously affect my gratitude that my wife received superbly effective, caring medical attention under very difficult circumstances. I am grateful to all the medical people who assisted both of us, including two psycho-therapists: a psychologist, Rudi Bauer, who gave me superb care (Bloch, 1997, <http://www.meditatenow.com/ch05.htm>) and another psychologist who cared for my wife and met with us a few times in joint session. In addition, I was very fortunate to have attended EST (Erhard Seminar Training, now called The Forum) and Lifespring, both marathon experiential courses. These controversial courses helped me greatly to understanding myself and to recover from misconceptions about my life and from the numbness that developed as a defense to my wife's illness and my son's serious difficulties (Bloch, 1997; <http://www.meditatenow.com/ch03.htm>).

Despite these superb therapeutic experiences, there were a few unresolved couples issues whose importance I never appreciated. This did not keep my wife and me from having a loving relationship, with many wonderful high points. But I now am aware that the relationship could have been even better.

At the time my wife and I adopted a child, we were unaware of the special problems of adoption. Since I now believe that

all adopted children have a pre-verbal awareness of abandonment by their natural mother (Maté 2000; Verrier 1999), our son was less able to withstand the special pressures of chronic illness and the fear that his mother might die, representing a second abandonment.

Illness also prevented my wife from giving our son the attention a healthy mother can freely give. We were not aware of the extent to which my wife would be handicapped as a mother or the extent to which the home of a chronically ill mother might be affected by tension and anger that is harmful for a child (Bowlby 1998; Maté 2000; Strong 1988; see also AAKP Patient Plan 2000). We also were not aware that the pressures of chronic illness would keep us from becoming educated, effective parents. While there may be some chronically ill mothers whose condition and strength-of-spirit permit them to be good mothers, caution should be exercised before adopting a child because the job of “mother” is difficult and demanding even for healthy mothers. Because the mother often is the primary attachment figure (Bowlby 1998), the father's illness may be important primarily as it affects the mother, but caution also should be taken about having or adopting a child into a home with a chronically ill secondary attachment figure.

CARETAKING DURING REPEATED MEDICAL SETBACKS

There are some chronically ill people whose perspective on their own illness permits them to live so fully that they inspire their families and loved ones rather than only burdening them (Kleinman, 1988). Two particularly noteworthy examples are Dr. Richard Kopp, a psychologist and author with kidney failure, and Louise Giroux, a psychotherapist and author with multiple sclerosis. However, it is more often the case that the course of kidney failure or end stage renal disease (ESRD) is traumatic, both for the patient and the caregiver. This may depend both on the perspective or “metaphor” that the chronically ill and their caregivers adopt (Kopp, 1995; Wilbur 2000), and also on the course of the illness (Strong, 1988).

Many complications occur during an extended course of kidney failure (Cameron 1996; Phillips 1999). No simple list is adequate to describe the events that occur. My wife's illness predated the use of erythropoietin (<http://wwwext.amgen.com/product/epogenHome.html>), so she suffered from extreme anemia, necessitating regular blood transfusions. She had osteodystrophy, a more profound deterioration of the bones than osteoporosis, and

she had so many small fractures of the rib that x-rays were incapable of identifying recent breaks. Osteodystrophy also contributed to several broken bones, including spontaneous breaks in both of her large leg bones and the upper bone in the left arm.

Access clotting and infection and the need for surgical “revision” or relocation was a regular source of anxiety and of frequent local, “relatively minor” surgery. My wife would sometimes say that she could not take even one more setback. For one ten year period, peritoneal dialysis was appropriate for my wife's kidney failure (Cameron 1996; Phillips 1999). In this process, dialysate was introduced into her belly through a surgically implanted catheter. The flesh around the catheter was an open wound, and my wife suffered several incidents of peritonitis, a life-threatening infection treated only by powerful intravenous antibiotics. My wife also suffered peri-carditis, a painful event that could be distinguished from angina and aneurysm only by the emergency catheterization, requiring the insertion of a plastic tube through a large artery in the leg and into the heart area, for necessary dye studies.

My wife also suffered systemic streptococcus infections, primarily from infections of access sites. These infections slowly hardened her heart valves.

Kidney transplants did not work well for my wife (Cameron 1996; Phillips, 1999). Data on the “survival” of transplanted kidneys are becoming more encouraging, making transplantation an increasingly attractive alternative, but my wife and I delayed transplantation, fearing complications that might lead to serious illness or death (Cameron 1996, Phillips 1999). My wife's first transplant occurred after 15 years of dialysis. The kidney never functioned fully, being lost through an incident of peritonitis. During this transplant, anti-rejection medications caused delirium, with psychotic symptoms and fear that she might commit suicide. A second transplant was given after my wife's 29th year on dialysis, when she was in a noticeably weakened condition. The second transplant led to a respiratory collapse and to death.

There were many other complications, each less “significant” than those already discussed. These complications included surgical alteration of the body, loss of physical vigor, brain deterioration causing speech seizures, an increased tendency to fall, and general seizures. The disease caused my wife to age more rapidly than others, so that hospital personnel often inquired whether my wife was my mother.

During my spouse's chronic illness, our energies were absorbed by her illness (Strong, 1988; Verrier 1999). Our son developed borderline personality disorder, bi-polar II disorder, and substance dependency. It was not uncommon for his crises to occur simultaneously with his mother's. I have a particularly vivid memory of leaving the hospital where my wife was being treated for seizures to take my son to the hospital because he was suicidal.

The need to deal simultaneously with both kidney failure and serious mental illness caused repeated trauma to everyone, including my wife, my son and myself.

THE NEED FOR TRUTH AND SENSITIVITY

Doctors ordinarily should tell the truth. Accurate information is needed both by dialysis patients and their spouses at different stages of the illnesses that precede kidney failure (McDaniel, Hepworth and Doherty, 1992). When a medical person is too gentle on the kidney failure patient, this conveys the implicit message that the doctor does not think he or she can bear up under the stress. This gentleness has the effect, therefore, of increasing anxiety when the stresses actually materialize. In addition, "gentleness" requires that inaccurate impressions be conveyed to the patient, assuring that these same inaccuracies will be passed on to those who care for the chronically ill.

For clarity, I discuss the illness in the following stages: (1) preliminary: illness that may progress to the stage of kidney failure, (2) imminent: illness resulting from serious loss of kidney function, (3) kidney failure: illness that would be fatal in the absence of dialysis or transplant, (4) complications: loss of some important bodily functions, including the skeletal system, the neurological system, the skin and the desire for sexuality, and (5) deterioration: loss of multiple bodily functions, necessitating adaptation to a restricted life and to approaching death.

Preliminary. At this stage, the physician knows that the patient has a disease that may at some point result in kidney failure. This is a shock, and the patient may cope with it by denial or by mourning the loss and preparing to accept the future.

Doctors monitor the patient carefully during this stage. It is common for the patient to be anxious. Blood pressure readings may be even higher than they should be due in part to fear from being in the physician's office. Doctors may suggest that the patient get a blood pressure cuff and measure blood pressure at home. This deals with the need

for an accurate blood pressure reading, but it ignores the need to address the patient's underlying anxiety, which has serious implications for coping with chronic illness.

The preliminary stage is an opportunity for a complete psychological diagnosis and for therapy that may help both the patient and prospective caregivers to face the future. It also is an excellent time to educate the patient and potential caregivers in detail about the likely course of the disease and the resources that are available to them. The best available sources are Cameron 1996, The Life Options Rehabilitation Advisory Council and AAKP (2000), and Phillips (1987). This education may be an inoculation that will prevent or reduce future trauma (Carson, Butcher & Mineka, 1998).

For prospective caregivers, the preliminary stage can be particularly important. It is at this time that a potential caregiver can assess the burden of care. Performing this assessment may, of course, have a negative social cost to others – because the "caregiver" may decide to make a limited commitment or even to leave, preventing society from depending on the potential caregiver. However, the welfare of the caregiver is also worth considering and no one should undertake such a heavy burden unless fully and accurately reflect on their situation.

Imminent. There are many physical and emotional problems that occur as kidney failure nears, including a change in patterns of urination, edema (swelling of the face, feet, belly and other areas), high blood pressure, loss of appetite or nausea, bad tastes (often described as an odor of ammonia), feeling tired or weak, mental changes such as an inability to concentrate or confusion, and headaches (AAKP, 2000; Cameron, 1996). Some patients may have spikes in blood pressure and retained fluid, threatening possible congestive heart failure.

The imminent stage is an important time for psychological adjustment. The changes in the body clearly signal that something "wrong" is going on. The sense of mortality may be heightened. There may be emotional symptoms, including severe anxiety or panic attacks. These panic attacks may be related to serious, physiological irregularities and they may trigger trips to hospital emergency rooms.

These are also times that people begin to consider the effect of chronic disease because their kidneys are failing. A woman patient may consider whether or not to bear a child. Consideration may also be given to adoption as an alternate way to add a child to the family (AAKP Patient Plan 2000).

However, an informed decision about adoption requires knowledge of the likely effect on an adoptive child of having a chronically ill mother with a diminished capacity for child care and an increased likelihood of dying (Strong, 1988). This may require detailed advance consideration of the physical limitations and risks of kidney failure.

Careful consideration should be given to the special needs of a child that may be adopted. Nancy Newton Verrier, a psychotherapist for adopted children and adults, believes that all adopted children suffer a “primal wound” due to a pre-verbal awareness of their abandonment by their natural mother. In her book, *The Primal Wound: Understanding the Adopted Child* (1999), she states that in 1985 adoptee's comprised 2 to 3% of the population of the U.S. but represented 30 to 40% of individuals found in residential treatment centers, juvenile halls or special schools. It is easy to believe this expert judgment since it also is known that certain prebirth experiences, including rhythmic and stress patterns, may be recognized or felt after birth (DeCasper and Fifer 1980).

Adoption in the home of a chronically ill person may cause a child to be fearful of a second abandonment on top of the relinquishment of her child by the natural mother. The child will be exposed to an increased risk of temporary and permanent “abandonment” by an adoptive mother. Even worse, the lack of time and energy that some mothers have may result in unintentional neglect, which may be experienced by the child as if it had been partly abandoned.

Even if it is the father who is the patient, serious advance consideration should be given before deciding to have or to adopt a child. It is less likely that the home will be relaxed and nurturing. The strain of illness may well make it very difficult to provide appropriate parenting.

In addition, serious attention needs to be given to changes in relationships resulting from kidney failure. For a married person, it is likely that the spouse will perceive that they have lost a healthy life partner (Strong, 1988) who could engage in sports and outdoor activities, travel without interruptions, and be free of health problems that affect sexual relations. Unless the couple's friends are untypical, there may also be some friends who find it uncomfortable to associate with a chronically ill person, whose condition sensitizes them to their own mortality. When the patient retains an active zest for life and a lively interest in activities, this effect can be minimized. But even if there is no alteration in the level of “zest,” some friends may still

drift away (Strong, 1988).

From a medical standpoint, this is also the time to evaluate different treatment alternatives. These choices are not always comfortable, as all of them involve risks and life style restrictions. Kidney transplants risk increased illness from the necessary use of immunosuppressive drugs, possible complications or death from transplant surgery, serious neurological side effects from immunosuppressive medications, transplant rejection, and the possible need for additional surgery to remove the transplant. The consideration of these alternatives may be stressful, calling for assistance from professional counseling or support groups.

Kidney Failure. Once kidney failure occurs, it is no longer a feared future event. It has happened. If the transition to kidney failure is well handled, dialysis may begin before the patient's health deteriorates, causing congestive heart problems or coma. My wife suffered kidney failure in 1970 when advanced planning was uncommon. She suffered a uremia induced coma.

It is during the kidney failure stage that patients often get their first exposure to a dialysis unit. One way to think of dialysis is as a special life-prolonging blessing. This positive point of view may be very helpful to a patient. However, many patients do not adopt such a positive metaphor.

In the dialysis unit, patients in various stages of kidney failure are treated in a large room. In that room, many clear plastic “lines” carry blood from the patient to the dialysis machine. During dialysis, “street” education begins, both for the patient and indirectly for the well spouse. The patient learns of complications experienced by other patients. In time, there are medical emergencies and news of the serious deterioration or death of fellow patients. Often this news of tragedies for friends is very difficult to bear. Patients with children may have special problems. If a child visits the dialysis unit, the exposure may be emotionally difficult. Likewise, keeping a child away from dialysis may have an impact because of the concealment.

It is also during this time following kidney failure that patients begin to adapt to dialysis. Individual patients may need either shorter or longer dialyses, depending on physiological needs and dietary habits. Some patients perform professional work while being dialyzed. Others sleep or try to sleep, being interrupted by nausea, dizziness and occasional cramps. Some watch television. Some suffer

from physiological symptoms after dialysis and “sleep it off” for two to four hours after each dialysis session.

If the patient chooses to have a kidney transplant, then they may leave dialysis for a time. For some, the transplant is fruitful. For others, the absence may be short and filled with disappointment. Often, after a transplant fails, the patient must return to dialysis and readjust – perhaps awaiting another transplant.

Deterioration. As the disease progresses, death is more likely than for those who do not have kidney failure. Thus, accommodating to one's own death is somewhat more urgent than for others. At times adjustment is unnecessary because of sudden death, which may occur for a variety of reasons, including infection and heart difficulties. If death does not occur, then physical deterioration is likely. The longer the patient is on dialysis, the more frequent and potentially more disturbing the deterioration. Under these circumstances, both the patient and the supporting spouse must adjust to a situation in which death is prematurely approaching and physical capacity is lost. They may “grieve on each rung of the ladder down” (Strong, 1988), giving them greater strength to face the future.

Continuing setbacks may be difficult to accept, even for patients and spouses with the best of attitudes and beliefs. Some patients may be unrealistically optimistic, seeing each event as independent and hoping or praying for a restoration of comparative health. After all, there have been better periods in the past. Why should those periods not recur in the future?

The spouse, on the other hand, observes the deterioration, sometimes more objectively than the patient. Emotionally this is difficult, but the caregiver is not personally losing physical capacity. Each loss means that caretaking becomes more arduous. There can be increasing resentment at the increasing caretaking load and, if it occurs, at the spouse's denial of the reality that is occurring. It is natural in this stage to be ambivalent toward the spouse. There is hope that the spouse will get better, at the same time wishing that the caretaking load would be lightened. The death of the spouse may be seen as an ambivalent event, marking the end of a loving relationship and also of a very great burden. It is also quite natural to long for another, lighter, more carefree relationship that is more reciprocal and that demands less day-to-day personal strength from the caregiver (Strong, 1988).

During the stage of deterioration, the patient may want to deny the seriousness of what is occurring. The well spouse may well want accurate information, even if the patient does not. If the spouse has already devoted many years of care, it is natural not to want to be a deserter in the final illness. On the other hand, if there is no way to estimate realistically how much longer the illness may last, then the spouse may decide to leave, as I did. Accurate information concerning the progression of the disease and the increased risk of mortality may well induce the caregiver spouse to stay the course – rather than to strike out on a new life while the chronically ill spouse is dying.

PSYCHOTHERAPEUTIC ISSUES

The principal therapeutic issue is that the extent of a caregiver's trauma may depend on perspective. New metaphors may be created by the well spouse, either alone or with professional help (Kopp, 1995). Depending on the course of the illness, this may make it possible for medical difficulties to be accepted and life to be more fully embraced, even with the difficulties.

With the losses and stresses caused by illness and its effects, pre-existing personal psychological problems, interpersonal problems or sexual problems may be even more difficult to resolve than if the couple were healthy (Life Options Rehabilitation Advisory Council and AAKP, 2000). For example, if the caregiver has been emotionally shut down before the kidney failure occurred, the increased tension may lead to emotional numbing (Bloch, 1997, <http://www.meditatenow.com/ch03.htm>).

I found that I was “proud” to be a caregiver. This means that I told others that I was doing well and had developed spiritual wisdom with which to cope with my difficulties. This was, however, only partly true for I was often close to tears. Fortunately, I benefitted from two major experiential courses, from the practice of meditation, and from superb individual psychotherapy. I also benefitted from physical exercise, which is both “palliative” coping (Lindqvist, Carlsson and Sjoden, 2000) and an effective way to maintain continuing health (Life Options Rehabilitation Advisory Council and AAKP, 2000; Strong, 1988). However, these practices did not remove the entire burden. It was only after my wife died and I developed a new, loving relationship that is not clouded by chronic illness that I appreciated the freedom and the fulness of life that I had been missing (Strong, 1988).

The “proud” caregiver may also be an enabler, preventing

the patient from full involvement and commitment to self-care (McDaniel, Hepworth and Doherty, 1992). Though the patient suffers from many ailments, including pre-existing emotional weaknesses, the patient and spouse may be capable of living a far richer, more fulfilling life than they choose. If the caregiver does too much, then the patient may give in to the natural tendency of sick children (or adults) to be overly dependent and “momish” (Bowlby, 1998). This may reduce the incentive to resolve pre-existing emotional weaknesses. It also may reduce the patient's self-esteem by validating their retreat from socially useful activities (Life Options Rehabilitation Advisory Council and AAKP 2000). According to Doherty and Baird (1983), “It is especially difficult diagnostically to differentiate families that are appropriately supporting their disabled member . . . from families that are over-supporting the members by keeping these persons dependent.” (See Life Options Rehabilitation Advisory Council and AAKP, 2000; Strong, 1988.)

An important couples issue may arise directly from the caretaking relationship. If the chronically ill person is upbeat and independent, then this issue may not be of major importance. However, if the chronically ill person is overprotected or emotionally dependent, then the caregiver may either suppress or repress emotional responses to avoid imposing extra, unnecessary stress on the spouse (Strong, 1988; Wilbur, 2000). While this coping mechanism may, to some degree, be “necessary,” it may prevent the couple from being equal partners and may prevent the patient from experiencing a sense of “communion” or a full loving relationship (Dreikurs, 1997; McDaniel, Hepworth and Doherty, 1992). The caregiver may try to bear-up emotionally for both of them and may even feel guilty that the patient suffers so much in their illness. In the process, there is an implicit contract that the caregiver is not entitled to express negative feelings toward the chronically ill person – including feelings of burden, embarrassment, lack of physical companionship, sexual frustration, or even the occasional wish that the stress might be relieved by the spouse's death. Indeed, this secrecy may be the hardest burden. Yet, sharing this feeling might be threatening to a dependent spouse (Strong, 1988; Wilbur, 2000).

Several different kinds of therapy are potentially helpful to the caregiver, including individual therapy, homogenous group therapy with other caregivers, general group therapy, family therapy, and a non-facilitated support group for the family or for the well spouse. Some support groups for the well spouse may be so concerned with the welfare of the

patients, that they may find it difficult to concentrate on the well spouses needs rather than those of the patients (Strong, 1988). Support groups appear to be effective, whether they are led by peers or by trained facilitators (Park & Folkman, 1997; Wilbur, 2000).

The literature also suggests that the caregiver take vacations from caretaking duties (Life Options Rehabilitation Advisory Council and AAKP, 2000; Strong, 1988). Consideration might be given to taking these vacations in pastoral settings, which are as relaxing as possible. Some caregivers may also choose, as I did, to have sexual affairs. While this is labeled immoral and may weaken or destroy the existing marital bond, some well spouses may consider this alternative to be attractive and acceptable. It may even be in keeping with the more democratic spirit of our times (Dreikurs, 1997). Some therapists may address this question by asking the well spouse the Rawlsian question, “What would you want the other to do if the situation were reversed (Strong, 1988)?”

When psychotherapy or support groups are utilized, care should be taken to inform the caregiver how much the work will focus on the patient and how much on the well spouse. In some groups and in family therapy, the caregiver's thoughts about dissolving their relationship may not be welcomed. Even in individual psychotherapy, the therapist may not be willing to fully explore all possibilities out of personal concern for the patient and a fear that a full exploration of alternatives may leave the patient without a caregiver.

FUTURE RESEARCH

This article is based on personal experience and on a few sources that address the long-term issues of being the well spouse of a kidney failure patient. Additional information could be gained by panel studies of well spouses and other caregivers, following them from the moment that they became aware that kidney failure (or other chronic illness) was a serious risk.

An important issue, highlighted in this paper, is the need to study the metaphors used by patients and by well spouses and the possible effectiveness of metaphor therapy. What effect do these metaphors have on the quality of life? How do metaphors change as time passes? How successful are well spouses in their marriage and in the quality of their lives? What limitations, if any, does the course of the illness place on the effectiveness of metaphors?

There also is a need for the publication of subjective story telling. What are the stories of well spouses and patients (Giroux, 1998; Kleinman, 1988; Strong, 1988)? In addition, it would be helpful to compile case studies written by knowledgeable therapists. It could be that the Well Spouse Foundation can play a role in stimulating these studies.

CONCLUSION

Spouses and others who care for patients with kidney failure have a variety of physical, emotional and spiritual needs that have not yet been adequately considered by medical and psychotherapeutic professions. A heightened awareness of these needs may be dawning. Well spouses experience stress from the multiple crises in the life of their loved one. Their needs are significant and are not always the same as the needs of the patient. Some of the impact on them depends on the metaphors they use to adapt to this trying life situation.

The well spouses of kidney failure patients and of other chronically ill people need separate, distinct consideration. As we become more effective in keeping the chronically ill alive for longer periods, the needs of their caregivers become increasingly important.

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