

Dialysis and People: The Value of Compassion and Empathy

By Herbert Pardes

Having recently experienced an excellent meeting on mental health, chronic kidney disease (CKD), and ESRD, I wanted to offer some thoughts about the extraordinary role that psychology and people play in the course of this illness and its treatment. I commend the Rogosin Institute for convening a marvelous group of leaders from various parts of the country to deliberate on these issues.

What does one learn from such a roundtable? First and foremost, that kidney disease has a potential for dramatically disturbing a person's sense of well-being. Many people with serious kidney disease are not aware that they have it. It comes as a shock. It is important to realize that the individual with CKD has substantial challenges to handle. It is not easy to travel. It is more formidable to take on a full day's work. Fear, unfortunately, arises from all kinds of unnerving developments in the course of CKD.

CKD can affect people of all ages. The psychological effects most frequently seen are depression, anxiety, and even post-traumatic stress disorder. Although florid psychosis is rare, depression is estimated as present in some 37% of dialysis patients. The greater the depression, the higher the risk for a downward course.

In the psychology of individuals, it is not uncommon for a patient to feel that their illness represents punishment for something. It is important to make clear that this illness has nothing to do with guilt and that there are

medical, biological, and psychological phenomena that cause CKD and its problems.

Another problem is financial support. Although Medicare provides payment for most patients with ESRD, practical help and advice from knowledgeable social workers or others who understand health care finance are important in reducing the stress.

There is an interactive effect in that the better the patient's attitude toward the illness, the better their course. Inducing people to take charge as opposed to feeling overwhelmed or devastated is critical. Finding ways to have the patients contribute is important. A person who feels consequential and that their life has value feels much better.

A good barometer for whether an individual will be able to effectively deal with kidney disease is how well he or she was able to cope previously. When people have successfully managed challenges before, there is a greater likelihood that they will be able to manage the life changes required by CKD.

Family support is critical. Family can be very helpful in not discouraging patients from work. Patients with CKD can travel, work, and have prospects of a lengthy life. There are CKD patients who have lived more than 40 years after diagnosis. That said, patients and their families need both physical and psychological space. Some patients manifest great anger, and it takes the care team as well as the family to be able to help patients deal with that

anger. Occasionally, a caring spouse can become a needy spouse, requiring more team support to get through that crisis. Attention must be given to the care partners as well as the entire family. There must be relief for them and understanding of how valuable they are. Group therapy can be very helpful.

So, how can we do this better? How can we bring as many caring people as possible into the situation to maximize the general welfare of the individual with CKD? Efforts should focus on strengthening quality of life by expanding the individual's interests and the opportunity for enjoyment and good social contact. We are clearly asking patients to do a lot, including taking on a tough diet, taking multiple medications, and altering their daily lives. We must treat all of our patients as human beings with all of the feelings, worries, good times, and bad times that all of us experience and do everything that we can to enhance their overall feeling of wellness, involvement, and importance. It is well suggested that the patient should feel that the various professional and nonprofessional caretakers are partners. We are in this together and will strive for the best possible life, much happiness, and positive experiences and developments in the setting of these very demanding challenges. ●

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Depression and Kidney Disease?

By Charlie Thomas

What do you mean my kidneys are failing?" "What is dialysis?" "Am I going to die?" "This can't be happening to me." "What about my family?" "I am afraid . . ." The diagnosis of kidney disease is a life-changing event for individuals and their families. Their entire world has just changed. They have lost their safe and secure view of their own sense of good health and well-being. Their sense of the future is not as certain. They are in crisis and grief. Crisis can be viewed as a critical event that requires people to develop new ways and acquire new skills to cope and manage a new normal. This new normal for a chronic kidney disease (CKD) patient requires many changes, including implementing a kidney-friendly diet and reorganizing time and plans to accommodate scheduled dialysis treatments.

The National Kidney Foundation (NKF) reports that 20% to 40% of people with kidney failure have depression, which may be related to a feeling of grief arising from a sense of loss (1). Kubler-Ross (2) described stages of grief and loss as denial, anger, bargaining, depression, and acceptance in her work *On Death and Dying*. For many individuals, these feelings do not fall into rigidly defined stages but are more like a "spiral of emotions," which increases and decreases depending on other factors, such as physical distress, social support, role conflict, loss of employment and income, and increased financial costs.

How can the kidney health care team help? The NKF's *Living Well with Kidney Failure* series notes how important it is for patients to be taught how to manage this new normal physically, mentally, and emotionally (1). This includes keeping track of laboratory results and working closely with their care team to set reachable goals. Critical steps in self-care management include taking medications as prescribed and managing any side effects. Many patients will need to make dietary changes to limit sodium, potassium, phosphorus, and fluid intake. Regular physical activity will help give energy and reduce stress. Managing stress helps patients improve both physical

and emotional health. Remaining connected to family and friends and continuing to be involved with enjoyable activities are important. Individuals with kidney disease should be supported to seek mental health services when needed.

Family members and caregivers are often the silent heroes for individuals with kidney disease. It is not uncommon for other family members to take over important roles that the person with CKD can no longer perform. The roles assumed may include responsibility for employment and income issues, transportation, household tasks and activities, and caring for children or dependent adults. Life partners may also be depressed by the changes that kidney disease brings to their intimacy. All of these changes often create conflict and stress. Family caregivers may be reluctant to disclose how stressed they are feeling to avoid placing an additional burden on the patient. The caregiver may even feel guilty or that they do not have a right to care for themselves and their own issues. Caregivers are at risk for depression and "burn out" if they neglect their own physical, mental, and social needs.

How can the CKD care teams help with the needs of the patient and caregivers? What are the "best practices" for incorporating these topics into patient and family education? First, early diagnosis and referral for CKD education can help many individuals prepare for the eventual transition to life with dialysis. Second, some people are diagnosed late in the course of the disease and face dialysis with very little time to prepare. These individuals must learn to adapt quickly. Third, patients and families must continue to cope with the evolving and changing demands of CKD and its treatment (dialysis or transplant) for the rest of their lives. This includes learning new skills to manage as one's physical condition changes and learning to cope with the ever-present emotional "ups and downs."

The dialysis center is often viewed as the "second" home for the dialysis patient, with other patients and treatment

staff seen as family. A meaningful and open relationship between patients and the CKD care team is important for successful self-management. Successful self-management can help patients cope with the physical and emotional aspects of dialysis and mitigate depression. The care team has an important role in educating and helping patients learn to cope. The book *Facilitating Treatment Adherence: A Practitioner's Guidebook* suggests several steps to help patients and families cope (3):

- Clearly introduce oneself and one's role with CKD patients, explaining how you can help.
- Explore patient's worries, goals, and expectations; empathize.
- Answer all patient questions.
- Avoid medical jargon; avoid being too technical.
- Discuss treatment pros, cons, and tradeoffs.
- Ask for the patient's suggestions and preferences and negotiate any disagreements.

Self-management is an important strategy to help CKD patients deal with the stress of treatment, including depression. Open and supportive communication and education between the individual with CKD and the care team are critical. ●

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References

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2. Kubler-Ross E. *On Death and Dying*, New York, Macmillan, 1969.
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