

SOUL OF THE MACHINE

By Ramiro Valdez

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s I entered the dialysis clinic one morning, I noticed that Elmer, the patient in the first chair, was not “connected” to the machine. His head hung

low and he appeared dejected. As a good social worker, I always make time for patients when they appear “down.” So, I pulled up a stool and asked how he was doing.

“My access is clotted again,” he responded. “This is the third time in a month I go into the hospital. I’ve been there more than at home. I don’t think I can take it anymore.”

I had known Elmer several years and was aware he was a man of faith and perseverance, but now, he appeared to have given up the will to live. He explained he would have to have surgery again and did not believe he would survive. Feeling at a loss for words, I sat close.

“Elmer, I cannot think of anything to do as your social worker. The only thing I can do for you right now is pray.”

He turned to me in surprise and immediately his eyes brightened.

“Oh, yes, would you?”

We prayed quietly for two or three minutes until his ambulance arrived.

Elmer died in a few days, but his widow sought me out a couple of weeks later. He had told her that I had done more for him that morning than anyone in his entire stay at the clinic. Of course, I had not, but I believe what he meant was that someone had helped

him meet a special need where no one else had tried.

Kidney failure, dialysis, frequent hospital stays—all of this can lead to negative emotions ranging from confusion to fear, to extreme anger and depression. Clinic staff assist patients in many ways except how to deal with these very common emotions. Because of this lack of support from the people around them, people often turn to their faith for spiritual sustenance.

A Religious Connection

It is common for people to turn to religion when there seem to be no answers anywhere else. Every culture ever studied by an anthropologist or excavated by an archeologist has practiced the worship of a deity. Throughout history, all people throughout the world nurtured the concept of a higher power, and practiced some form of spirituality. This is never more evident than when people are struck with an incurable illness.

Some people are angry and blame a higher power for allowing the illness to happen to them. Others expect a miracle, and pray to bring dead tissue back to life. Still others ask for help in coping, and use kidney failure as a way to help them grow spiritually and emotionally. Whatever the nature of the response, practically everyone who has end stage renal disease ponders the meaning of life, death and afterlife.

It would seem that professional staff at a clinic would try to help in this area. We offer help with psychological adjustment, finances, medicine, diet and even exercise. Why not spiritual needs?

We hardly ever do. Most of us avoid it because chronically sick people can get desperate. If we suggest that a patient goes to his place of worship to pray, they tend to ask for a healing. I have witnessed two people who “claimed the victory” and refused further dialysis treatments, no matter what I, or their doctor, said. One of them was brought to an emergency room three weeks later, confused and having uremic seizures. The other was a little more stubborn and she died claiming that God had healed her.

A Miracle

I tell people seeking miracles that it already exists. I explain that Willem Kolff worked long hours with little pay to develop the first artificial kidney, or dialyzer. I point to the dialyzer with the patient's own name on it and say, "Here is your miracle, if you will accept it." I speak of Belding Scribner, Eli Friedman, John Bower and other people who have worked tirelessly with few rewards on behalf of kidney patients. Is this dedication to fellow human beings not the work of God?

Some people refuse to hear this. As their miracle, they will only accept having their kidneys "raised from the dead." Sadly, I have seen patients become embittered and angry with God for not doing things their way.

Helping patients come to terms with their spiritual needs can diffuse the anger. There are two processes: one, personal soul searching, and two, accepting the help of others.

Soul Searching

Invite patients to do the following:

1. Stop asking, "Why me?"

Write down the names of five people you love dearly, and then add your own name. Now let's suppose that the powers of the universe give out so many cases of kidney failure per year, per city, and they had to pick someone on this list. Who do you think it should be? Most patients would rather suffer a disease themselves than have it afflict their children or spouse. The point? Stop asking, "Why me?"

2. Stop trying to figure out what you did to deserve this fate.

You did nothing. No one deserves renal failure. If you are diabetic or have high blood pressure, there may have been preventive measures that would have postponed the onset of the illness—but not for very long.

This illness is no one's fault, so stop trying to place blame elsewhere. It simply was diabetes, high blood pressure, cysts on the kidneys, or something else. It just happened. That's all there is to it. If you're angry, talk to your doctor or social worker and ask for suggestions on how to control this negative response.

3. Return to the basics.

Start reading literature from your place of worship. Make time to pray. If you only have 10 minutes to pray, talk for five and listen quietly for five. This "listening" part is more like meditation, which all religions recommend. Instead of asking "why," or "do this," or "give me that," time spent in quiet reflection with a willingness to listen is often the most rewarding part of prayer.

Meeting Spiritual Needs

There's no mention anywhere in the Health Care Financing Administration's ESRD regulations about prohibiting clinics from making appropriate referrals to houses of worship—if a patient requests it (Hall, 1999). Nor is there any part of the Medicare contract that says staff must avoid asking patients about their religious preference, or if they have spiritual needs (Hall, 1999).

The professional standards of practice recommend addressing the needs of the "whole" person. Yet, while there is reference to the psychological and social needs of a patient, it does not mention spiritual needs. Certainly, as licensed professionals, we do not deny that religious beliefs and spirituality are an integral part of the psychological, social and cultural nature of a patient. It is safe to say that professional standards do not prevent us from at least recognizing the spiritual needs of our patients as a part of the "whole" person.

For those patients who already have a house of worship, staff can request a call or a visit. I have made many such calls and without exception, I have received a warm and positive response from the clergy, no matter what religion.

I believe staff needs to ask about spiritual matters because some patients lack the courage to return to a spiritual connection. If staff does not bring up the subject, the issue could remain unresolved. In my opinion, unmet needs contribute to emotional problems and could even lead to a major depression.

Clinics should safeguard a patient's right to read spiritual material during dialysis, or to pray. Patients also have a right to be visited by clergy during regular visiting hours, but when there are problems that require nursing intervention, he will need to leave quietly. And if treatment scheduling interferes with religious holiday observances, re-schedule the treatment. Also, make allowances for changes in eating patterns for such holidays as Lent, Ramadan, Yom Kippur, and days of fasting.

Importantly, it is not appropriate for professionals to force religion on a patient, or to allow other patients to behave in this manner. It's not fitting to sermonize. It is, however, appropriate to ask about a patient's religious preference, and to make a referral. If there is no religious preference, the matter simply is dropped.

Spiritual Responsibility

If patients wish to pray together, they must do so responsibly and not pray so loud that they disturb other patients or staff. It is best for these visits between patients to allow for occasional interruptions for such things as physician's rounds or blood

pressure precedures.

Praying for a cure and then discontinuing dialysis by faith is not responsible spirituality. Most staff members will shy away from spirituality for fear of this type of behavior. When patients tell me they have strong faith and believe God will cure them, I always say "I have never seen it, but I hope you're the first one. Meanwhile it will not hurt you to follow these suggestions." Then we talk about dialysis compliance.

This brings us back to all the wonderful men and women who have unselfishly dedicated many years to improve the quality of the lives of other people. This may well be the prayed for miracle. **FPO**

About the author:

Ramiro Valdez is a social worker with 12 years experience in various dialysis clinics and six years in mental health clinics. Currently he is Patient Services Coordinator for the ESRD Network of Texas in Dallas.

Reference:

Hall, Kay, ESRD Technical Advisor, Health Care Financing Administration, Southern Consortium. Personal Communication, November 4, 1999