As you read below, you may wonder why this essay is here in the middle of BLOOD PURIFICATION, a journal dedicated to providing cutting-edge scientific information on the practical aspects of hemodialysis, peritoneal dialysis, hemofiltration and plasma filtration. This work is vital in that it is a yard marker toward the goal to be achieved. After all, unlike many other diseases, the highest goal in the treatment of kidney disease is not to provide a cure, but to assist an individual in returning to a state capable of service, a life with purpose and with meaning carried out with a sense of joy. If we lose sight of that, then we lose track of what we are doing. The goal is not to achieve a number; it is far above and beyond that. Hopefully, what you will read below will be a confirmation of this fact.

My life’s journey in the medical world began at age 4 when I contracted a streptococcal infection and was subsequently diagnosed with a ‘kidney infection’. My childhood included annual visits to the nephrology clinic at the Hospital of the Albert Einstein College of Medicine in New York, bringing along a 24-hour urine collection. I was vaguely aware that this was not something the other children in my class did.

Just as I began dealing with the typical troubles of adolescence, I was hit with a few highly atypical ones. One, it was discovered I had a severe to profound bilateral hearing loss. One ear would require a hearing aid. The nerve in the other ear was damaged to the point that it would not benefit from amplification. Two, results of a kidney
biopsy revealed the alarming news (kept from me for as long as possible) that I had irreversible kidney damage that had progressed to the point that I would require kidney dialysis in a few years. To an 11-year-old girl, the sudden necessity of having to wear a hearing aid was already bad enough.

By age 14, I underwent surgery for an A-V fistula and the following year, thrice-weekly dialysis treatments began. I don’t have words to express the fear and horror I felt at the notion of requiring a machine to live. I held on to what I was told: I would receive a kidney transplant and that would be the solution. Nothing could have been further from the truth and looking back, I’m glad I had no idea what was coming. I did indeed receive a transplant a few short months later. Weeks at a time in the hospital, long periods in ICU, watching my body undergo all manner of side effects from the medications to the point where I became unrecognizable to my former teachers; the worst was yet to come; after three short months, I lost the transplanted kidney and almost my life!

I returned to the dialysis unit but this time having learned a few things. I was not going to necessarily accept everything I was told. When I was told my fistula was too weak and too underdeveloped to be used as a reliable access, I chose to learn to place my own needles. As a result, it matured and developed. When I had a parathyroidectomy and was told afterwards that I would require exploratory surgery to locate the wayward fourth nodule, not being interested in participating in this risky (and at what cost?) enterprise, I declined.

I secretly prayed to simply be able to begin college and perhaps even complete my studies, and so I set my sights on UCLA in Los Angeles, where my sister had moved some years earlier. Once there, my health stabilized and though severely anemic, I was able to carry a full course load.

One day in 1979, as I was doing research for a paper in the psychology library, I found myself drawn to researching the psycho-social effects of kidney disease, looking up key phrases like chronic illness and dialysis. And it was there that I first saw in the literature what the dismal effects of kidney disease were: widespread depression among the dialysis population, commonplace retreat from the mainstream world, and an average survival rate of 5 years [1]!

I stared at that bit of information in shock. This was a question I had been too afraid to ask before. And there was the answer staring up at me in black and white. I had already been on dialysis for 4 years. But wait! I had taken a course in statistics. I knew something of the mean, median and mode. And thankfully, my rational mind began to kick in. If the average survival rate was 5 years, that meant half the population survived less than 5 years and half survived greater than 5 years. I was already heading toward 5 years. There was only a finite amount of space on the left side of that bell curve and I much preferred being on the right side, where the tail could stretch out for a long ways. It was then that I decided that I belonged with the group that lived greater than 5 years.

Only recently, I came across an essay written by the scientist Stephen Jay Gould and published in 1985 in Discover Magazine, called ‘The Median Isn’t the Message’ [2]. Dr. Gould wrote about his personal experience with cancer and came to a similar conclusion of his supposedly dim life expectancy prognosis, which he explained in this highly scientific yet accessible essay. He had been reading similarly dire statistics that his rare and dangerous cancer had a median survival expectancy of 8 months after diagnosis. His conclusion was that, given a number of variables in his favor, he belonged in the long right-skewed tail of that bell curve. Dr. Gould, in fact, lived a full life for 20 more years, only to succumb to an entirely different cancer. It seems that I too, after having lived with dialysis as part of my life for more than 40 years, am living in a similarly right-skewed tail.

Relevant to our discussion here, Dr. Gould also stated that attitude was a key factor in lengthening the tail of the bell curve, including a willingness to take responsibility for one’s own care, the acquisition of knowledge, and a desire to see the challenging situations through. Yes, yes and yes! I am so grateful for also being on the right side of that bell curve.

And so it went. Many years more of in-center dialysis rolled by – seeing me through college, getting a graduate degree in special education, being employed in full-time work with deaf children and their parents, and teaching at the graduate school at USC’s School of Education. Along the way, there was a second attempt at transplantation that unraveled even before it could begin. And then a wonderful era – more than 12 years’ worth – of CAPD without a single incident of infection and with the original catheter the entire time.

After my third failed attempt at transplantation and its challenging aftermath, it became clear that transplantation was not a viable option for me. I would need to fight to get the training I desired to do nocturnal home hemodialysis (NHHD). Research clearly showed all the health benefits, both short- and long-term, of NHHD [3]. It would not reverse the advancing amyloid situation in my body but it would give me the greatest level of health pos-
sible with dialysis, prevent me from being debilitated by the treatment both during and after, and afford me the ability (and appetite) to eat a wide range of wholesome and healthy foods.

Along the way, I took up the cause of people living with dialysis and transplantation, providing education and encouragement through seminars and newsletters. And I began my current work, speaking at professional conferences, advocating for raised expectations, individualization of treatment and optimal outcomes in the renal field. Now, the documentary I am at work on, Life on the Bridge, is coming to fruition. It shares the message of overcoming obstacles to create meaning and joy in life.

I have come to some conclusions. Doctors come to the table with years of acquired knowledge and a high degree of skill. Patients present to them their own life experiences. The desired outcomes will be obtained only by engaging with the individual who is facing the challenge to learn from their life experiences. Solutions will develop when both parties are able to listen to each other with empathy to find the individual therapy that has the best chances of success for that person. My message is to encourage horizontal communications, rather than vertical only, from the top down.

It is said that life itself will eventually teach you all that you need to know in order to live it. The trick is being open and living long enough to find out. I am very glad to be a work-in-progress.

Disclosure Statement

None.

References