Over Four Decades of Life with Dialysis
A Tale of Self-Empowerment

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Introduction

A young patient with progressive kidney disease may be best served with successful long-term kidney transplantation when kidney failure develops. Should a living donor transplant be unavailable and the wait for a deceased donor transplant prolonged, a strategic dialysis plan must then be developed by the patient in collaboration with the nephrologist and continually updated as the patient grows and circumstances evolve.

One of the authors of this article (J.W.), now age 61, was diagnosed with biopsy-proven GN at age 7. As sensorineural hearing loss occurred, Alport syndrome became the underlying diagnosis, and dialysis was started at age 15 in 1975. An arteriovenous fistula was placed in 1974 and had to be replaced with another arteriovenous fistula in 1975. Kidney transplantation was performed in 1975 but failed in 3 months. A second transplant in 1986 never functioned. Thereafter, continuous ambulatory peritoneal dialysis (CAPD) was successfully utilized for over 12 years. A series of musculoskeletal difficulties began in 1993, and surgical specimens demonstrated evidence of amyloid deposition.

A third transplant in 2000 lasted only 3 months. Pathology revealed antiglomerular basement membrane nephritis. CAPD had to be terminated in 2000 secondary to peritoneal membrane failure. At this time, J.W. returned to in-center hemodialysis but was resolved to find a facility that would train her for nocturnal home hemodialysis (HHD), which she determined would provide her with the greatest long-term benefit. One was eventually found in 2002 where the nurse/administrator agreed to initiate a training program for this modality, which has been maintained to the present. Her schedule has been 7-hour dialysis sessions every other night.

Major obstacles have included hip arthroplasty in 2010 complicated by a stage 4 gluteal pressure ulcer requiring an 11-week hospitalization and intensive operative debridement. In 2011, spontaneous tibia-fibula fractures secondary to severe osteomalacia required both calcium and phosphate dialysate supplementation, with eventual healing over a prolonged 16-month interval (1,2). Progressive difficulties secondary to neuromuscular dysfunction and severe retinopathy with progressively dimmed vision continue to require creative adaptive solutions.

At the patient's direction, fistula self-cannulation was initiated in 1976 following numerous incidents of cannulation difficulties by dialysis facility staff. Subsequently, there have been no fistula infectious or obstructive problems. During the 12-year experience with CAPD, J.W. experienced no exit-site, catheter, or peritoneal infections.

During these 46 years, her life has continued to be full and includes marriage, a bachelor's degree, two master's degrees, and, now, pursuit of studies leading to rabbinic ordination. She has traveled to Israel on five separate occasions and visited France, utilizing either hemodialysis or CAPD. BP has been 125–135/75, and weight is stable at 56 kg. Representative recent laboratory studies include BUN 36–48, creatinine 3.2–3.7, albumin 4.4, Kt/V 3.0, urea reduction ratio 85, calcium 8.8–9.8, phosphate 2.8–5.4, parathyroid hormone 42, hemoglobin 11–12, aluminum 12, and β2-microglobulin 22. It has always been clear to J.W. that her dialysis therapies were in support of creating as full a life as possible, including serving as an adjunct associate professor in the Graduate School of Education at University of Southern California, as a health advocate, and now, as a certified community chaplain.

Discussion

What factors resulted in the unprecedented longevity experienced by J.W.? Most important was her unwavering attitude toward her health care burdens, best expressed by Austrian neurologist, psychiatrist, and Holocaust survivor Victor Frankl (1905–1997): "The last of the human freedoms, to choose one's attitude in any given set of circumstances is to choose one's own way" (3). J.W. has always felt above all else that an individual must have meaning and purpose in life as the reason to keep adapting. Thus, she began her education in self-cannulation at the age of 16, and thereafter, relentlessly continued to take responsibility for her care through the comprehensive acquisition of knowledge in all aspects of kidney disease management. She has, in effect, successfully become dialysis nurse, technician, dietitian, and personal health care manager.

J.W. states

I knew that no one had a greater investment in my well-being and quality of care than I did. It followed then that I must do whatever was in my power to manage my treatment with meticulous attention, whether [hemodialysis] or CAPD. Over the years, I encountered resistance from nursing and administrative personnel with regard to dialyzer and equipment choices. As home hemodialysis utilization is very low (<2% of patients on dialysis in the [United States]), dialysis facility infrastructure is limited and less able to provide flexible patient support (4). There were occasions when I had to switch dialysis facilities because of disagreements with administration over requests made for changes in their support. I am grateful to have benefitted from four special nurses and a few physicians along the way who gladly shared their expertise with me. It is to this small cadre of individuals that I owe a huge debt.

As J.W.'s nephrologist, F.G.S. learned that he was able to trust not only her technical skills but also her consistent ability to make both correct assessment and judgment decisions. This further increased physician confidence that she would be able to enlarge her assumption of increased self-care responsibilities with time.

Very long-term survival for individuals with kidney failure utilizing various dialysis modalities is possible, and J.W. has survived longer than previously reported patients (5). Two factors have been largely responsible for this extraordinary achievement. The first factor is patient empowerment with engagement in the full spectrum of the complex management of kidney failure. Shared decision making with active participation, rather than being the mere recipient of administered therapy, is of great value to patient longevity and freedom from the potential adverse effects of necessary treatment. This has been suggested by studies evaluating multiple outcomes in the management of hospitalized patients, diabetes mellitus, medication compliance, determination of dialysis option selection, and peritoneal dialysis (6–8). Patient hospitalization, mortality rates, and missed treatments are lower in self-care hemodialysis as compared with patients managed in center by facility staff (9,10). Patients actively involved in all aspects of dialysis therapy can better determine or later revise their treatment option decisions.

The second factor is the development of a very close personal working relationship between patient and nephrologist consisting of respect, mutual trust, and sharing of responsibility. The physician's role in providing encouragement with confidence-building measures can lead to sufficient patient independence, allowing successful transfer from dialysis center to home dialysis.

Although most patients starting dialysis therapy in the current era are elderly, there are significant numbers of younger patients in whom the potential for successful kidney transplantation may be limited (*e.g.*, immunologic or surgical obstacles or personal choice). The recognized objective for these individuals is achievement of decades of life, which will require creative management and strategic individualized optimization of treatment design.

Standard in-center hemodialysis care schedules provide adequate care for a number of years; however, over decades, this may be insufficient, and dialysis time may need to be increased. Although current availability of in-center dialytic schedules to fit this need is extremely limited in the United States due primarily to payor reimbursement restrictions, longer dialysis times in many other countries have been associated with both improved long-term clinical outcomes and patient survival (11). HHD and especially nocturnal HHD are associated with improved BP control, regression of left ventricular hypertrophy, improved biochemical parameter control, better kidney disease quality of life, and shorter recovery time from dialysis treatments (4).

Because most individuals start therapy at a time filled with anxiety, helplessness, a sense of being overwhelmed, fear, and, possibly, a degree of depression, nephrologists can better support their patients by advocating mutual patient ownership of their care together with their nephrologist as being a key to optimum outcomes, and by providing extensive education as well. Being totally inexperienced in this new world of highly technical therapy requires sufficient time to shape increased patient comfort in the provision of care. Sufficient experience can be gained, advancing from passive to active participation in all components of dialysis care and resulting in dialysis success as patients learn that this is directed at the goal of keeping them well so that they can enjoy a truly rewarding life.

Long-term survival on dialysis, together with a full and rich life, for individuals with kidney failure is achievable. Personal empowerment with the goal of eventual self-care promotes creative and strategic dialysis treatment through the stages of each patient's dialysis course. When linked with a well-developed relationship between patient and nephrologist, optimization of clinical outcome can be attained. This approach should be noted by nephrologists, primary care physicians, nurses, patients, and policy makers. We believe that this strategy, if increased to even 10% of the dialysis population, could open a pathway to healthier living for approximately 50,000 people in the United States. A standard "one-size-fits-all" dialysis process is clearly insufficient for patients looking forward to a long and fulfilling life alongside the presence of kidney disease.

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