
Home Hemodialysis: A Patient's Perspective

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This is a personal story of a member of a family with hereditary nephritis. My oldest brother died in 1946 before there was any dialysis or transplantation in the United States. My other brother died at the age of 22 in 1960 after unsuccessful kidney transplantation. I developed renal failure in 1980 and was lucky to survive due to the combination of several factors. The first, and most important, was the choice of home hemodialysis, which offers the longest patient survival of all dialysis modalities. The second was the help of my wife, who is my dialysis partner. The third was my conviction that it is not possible to get too much dialysis. I took control of my treatment and insisted on having the largest available dialyzers and performed long dialysis sessions. I was able to continue to work for the first 15 years on dialysis. As I look to the future, I am excited about the prospect of daily home hemodialysis, because I believe that this therapy will offer more efficient treatment and a nearly normal diet.

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Hereditary nephritis, history of dialysis, dialysis efficiency

My perspective

As I look back at my family's history of chronic hereditary nephritis from the vantage point of 1997, I am truly amazed at what I see. Although I didn't realize it in 1963 as a 17-year-old, my first nephrologist, Dr. John P. Merrill, was arguably the nation's first nephrologist. The specialty of nephrology was not even known then. My surgeon, Dr. Joseph Murray, also became quite famous when he received a Nobel Prize in Medicine in 1990 for his early work in renal

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transplantation. My parents were faced with the tragic situation of having their only three sons afflicted with hereditary nephritis, but they did the best they could by giving us the best medical care that was available at the time. Even so, only I survived to tell the story, and that was made possible by the technical marvel of chronic hemodialysis treatments and the political climate that made the Medicare end-stage renal disease (ESRD) program available.

My brother Billy died with ESRD at the age of 15 in 1946 before there was any dialysis or transplantation in the United States. My brother Tommy died at the age of 22 on 30 March 1960, 27 days after Dr. Belding Scribner dialyzed the world's first chronic hemodialysis patient, Mr. Clyde Shields, on 3 March 1960. Although it can only now be seen with hindsight, Tommy just missed the window of opportunity for lifesaving chronic dialysis. Tommy received what was then a highly experimental treatment for kidney failure: a kidney transplant.

Tommy made two trips to Boston's Peter Bent Brigham Hospital (PBBH) in 1960. On the first trip he was accompanied by a prisoner from the Georgia prison system who had "volunteered" to donate a kidney. This was a desperate attempt by my father to save his son and involved some political contacts with the head of the Georgia prison system and the support of a marvelous internist in Atlanta, Dr. Arthur Merrill, Sr. (no relation to John Merrill). Although the prisoner had been thoroughly examined by Dr. Merrill in Atlanta and pronounced healthy, he was found to have hypertension and was rejected as a possible donor by the team at the PBBH. Needless to say, my parents were very disappointed after making such a heroic effort to save Tommy's life. They always suspected that the real reason was not medical.

The family returned home to Rome, Georgia. Tommy was maintained by several infrequent hemodialysis treatments at Atlanta's Piedmont Hospital, which had a Travenol tank dialysis machine. Each treatment required a surgical procedure for blood ac-

cess. I remember Tommy and my father coming home from one of these treatments. As they were greeted by my mother Tommy said, "Momma, that treatment is worth a million dollars." These were prophetic words in 1960. ESRD patients like myself who began dialysis under Medicare coverage and who have never experienced rationed treatments will never fully understand or appreciate what these treatments mean to us, or what it would be like to be told they are ending.

Later, after the family returned home from the first trip to Boston, Tommy's family physician in Rome, Dr. Tom Moss, Jr., received a call from Atlanta saying that there would be no further dialysis treatments for Tommy. The family physician was told that there were other patients who had the prospect of receiving a kidney transplant and that these patients would receive priority for treatment on the one dialysis machine that the hospital had. Ironically, later in the same day, Dr. Moss received a call from Boston saying that a kidney donor had been found for Tommy. Arrangements were immediately made for a Navy plane from Dobbins Air Force Base in Marietta, Georgia, to come to Rome to fly Tommy to Boston. Military regulations required that a physician be on board, and Dr. Moss volunteered to make the flight.

Tommy received a "Matson kidney." This was a kidney from a hydrocephalic infant on whom the neurosurgeon, Dr. Donald Matson, had had to sacrifice the child's kidney in order to construct a cranial drainage tube into the bladder to save the infant's life (1). Tommy was one of 11 patients on whom the Boston team attempted total body irradiation for immunosuppression at a time when there were few, if any, immunosuppressive drugs available. Only one of these patients survived. Tommy died about 20 days after the transplant from complications due to the total body irradiation.

I was 14 when Tommy died, and it was only 2 years later when the laboratory in Rome mistakenly determined that I had elevated BUN (blood urea nitrogen; it was then called NPN, nonprotein nitrogen). My parents understandably panicked, and I, too, was whisked off to Boston. There it was determined that the laboratory in Rome was in error, but since I was there, and since the outcome of my disease was all too well known, Dr. Merrill proposed an experimental treatment. He thought the illness was autoimmune and that my kidneys were being attacked by antibod-

ies in the same way in which a transplanted kidney is attacked by antibodies. Since the spleen was thought by the Boston group to be a major source of antibodies, I had a splenectomy performed by Dr. Joseph Murray and was treated as a transplant patient. I received the new clinical trial agent Imuran, massive doses of prednisone, and actinomycin. The treatment did not cure my kidney disease, and I grew up expecting to die in my early 20s.

When I was a graduate student at Georgia State University in Atlanta in the mid-1970s, I visited the dialysis unit at Grady Memorial Hospital. Because I wanted to get a totally frank view of dialysis, I told them I was a student doing a paper on dialysis. The nurse told me: "They have all kinds of problems, and they just go downhill." So, when I began dialysis in 1980, I thought I would live only a few years.

My long career of survival on dialysis was set in motion when my nephrologist in Rome, Dr. Charles Nuttall, recommended me for home hemodialysis. I knew I didn't want a transplant, because at the time graft survival at one year was only about 50%, with patient mortality nearly 30% (2). Also, I'm sure the bad memories of my brother's unsuccessful transplant contributed to my reluctance to seek transplantation. I did investigate continuous ambulatory peritoneal dialysis (CAPD) at the time. I went to Atlanta and talked to a CAPD technician. He explained the therapy thoroughly to me, and I returned home. I wrote him a letter and asked a few more questions, but did not receive a reply. I took this lack of response as a sign that I should not pursue this therapy option, even though I am now aware that he was probably too busy to reply and may not have had the administrative resources to write back. Anyway, this turn of events was a stroke of luck for me, because I now know that home hemodialysis, not CAPD, offers the longest patient survival (3-7). Thus my therapy choice was home hemodialysis (HHD), and this was the right choice for me.

As soon as my wife and I completed HHD training, we went on a "dialysis cruise," which I learned about through Dr. Nuttall. Here, chance put me in contact with Dr. Peter Lundin, who filled in for the scheduled nephrologist who had to cancel at the last minute. This chance meeting of Dr. Lundin had a profound influence on me at this early impressionable stage of my dialysis career. The fact that he had been on di-

alysis for 17 years at the time was amazing to me, because I thought only a few years of survival on dialysis was possible. He also taught me to get the most efficient dialysis treatment possible by using the largest dialyzers available. He was a good role model for me; he was energetic, optimistic, and continued to work full-time as a nephrologist. I returned home much more confident and insisted on having the largest dialyzer obtainable, which my nephrologist agreed to. I learned that it was not possible to get too much dialysis. Oddly, my nephrologist's partner told me I didn't need a larger dialyzer, which advice I ignored, and in the process I apparently offended him. I was beginning to take control of my treatment, which is the hallmark of individuals on home hemodialysis and is, perhaps, one of the main factors responsible for the longer survival of HHD patients like myself.

As I adjusted to HHD and became more skilled and knowledgeable about my treatment, I gained confidence. In 2 years I had the urge to take the dialysis equipment and travel. Early attempts to arrange dialysis in another facility for simple trips were largely unsatisfactory, and it was then that I realized that motor homes already had the three things that were essential to dialysis: water, electricity, and a drain. We bought a small motor home, made the necessary plumbing and electrical modifications, and hit the road. We are now in our second motor home, having had the first one for 10 years. We have traveled all over the country, and this freedom to travel has meant everything. It has given me a great sense of psychological freedom, knowing that I can travel and vacation as I had prior to ESRD.

The main reason I chose HHD was that it would allow me to continue to work, since my dialysis facility did not have an evening shift. I worked for the first 15 years on dialysis. This allowed me to remain a contributing member of society and gave meaning to my life. It also helped to make dialysis a necessary chore rather than the focus of my life.

One of the disadvantages of HHD is the need for an aide to assist with the treatments. I have been lucky to have a dedicated and loyal spouse who has helped me day in and day out all these years. Such a family member is rare indeed. I believe that one of the salient shortcomings of the Medicare ESRD program is that it does not allow coverage for a paid aide so that more patients could choose HHD and receive its many

benefits as well as providing needed relief for family members.

I believe that being able to maintain one's normal routine in one's own home, thus avoiding being in an institutional environment three times a week, is one of the more important advantages of HHD. Besides, most adults want to feel that they are in control of their lives. How could one feel in control of one's life while being institutionalized three times a week? Home hemodialysis has offered me long survival, the ability to maintain employment, and a satisfying lifestyle. Things could be better for me, though, and many more patients could be eligible for HHD. Here is my wish list for change:

1. Nephrologists and other physicians responsible for the care of dialysis patients should think in terms of long-term survival of their patients. If they think this way, then there would be many more patients on HHD with natural arteriovenous fistulas (8,9), rather than in chronic dialysis facilities with artificial grafts.
2. Nephrologists should prescribe large, biocompatible membrane dialyzers and long dialysis times (4 hours or more). It is well established that more dialysis is better than less (3).
3. Medicare ESRD coverage should provide for paid home dialysis aides. This would allow many more patients to receive the benefits of HHD and would provide needed relief for family member aides.
4. Dialysis facilities should have a more open policy concerning transient dialysis patients. This would make travel for patients much easier.

As I look back 37 years to when I developed hereditary nephritis, I am thankful to be alive. I could easily have followed the fate of my brothers were it not for the successes of the ESRD program. The survival of hundreds of thousands of ESRD patients like myself rests on the shoulders of many talented physicians and scientists who made the technological development of chronic dialysis possible. Their work, combined with the political victory of the passage of Medicare coverage of ESRD in 1972, has made it all possible.

As I look to the future, I am excited about the prospect of daily home hemodialysis (10,11). I believe this therapy will offer me and other patients like me much more efficient treatment and a nearly normal diet. I believe we will find daily treatment to be

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worth the many benefits, especially if those treatments are much shorter. I sense that we are on the threshold of a revolutionary advance in dialysis therapy.

References

- 1 Moore FD. A miracle and a privilege recounting a half century of surgical advance. Washington, DC: Joseph Henry Press, 1995.
- 2 Oberley ET. Understanding kidney transplantation. Springfield, IL: Charles C. Thomas Publisher, 1987.
- 3 Charra B, Port FK, Berger EE, *et al.* How can the mortality rate of chronic dialysis patients be reduced? *Semin Dial* 1993; 6:91–104.
- 4 Delano BG. Home hemodialysis offers excellent survival. *Adv Renal Replace Ther* 1996; 3:106–11.
- 5 Delano BG, Friedman EA. Correlates of decade-long technique survival on home hemodialysis. *Home Hemodialysis International*, Vol. 1, 1997
ASAIO Trans 1990; 36:M337–9.
- 6 Oberley ET, Schattell DR. Home hemodialysis: Survival, quality of life, and rehabilitation. *Adv Renal Replace Ther* 1996; 3:147–53.
- 7 Oberley ET, Schattell DR. Home hemodialysis and patient outcomes. *Dial Transplant* 1995; 24:551–5.
- 8 Kaufman JL. The decline of the autogenous hemodialysis access site. *Semin Dial* 1995; 8:59–61.
- 9 Moore ED. Surgical approach to arteriovenous access for chronic hemodialysis. *Semin Dial* 1996; 9(Suppl 1):S14–16.
- 10 Kenley RS. Tearing down the barriers to daily home hemodialysis and achieving the highest value renal therapy through holistic product design. *Semin Dial* 1996; 3:137–46.
- 11 Twardowski ZJ. Daily home hemodialysis: A hybrid of hemodialysis and peritoneal dialysis. *Adv Renal Replace Ther* 1996; 3:124–32.