Hemodialysis at Home: The Problem Patient

Kathleen A. Molenda B.S.N. and Peter Ivanovich M.D.

Medical Service, V.A. Research Hospital
Section Nephrology/Hypertension
Northwestern University, McGaw Medical Center
Chicago, Illinois

What do you do about a 210 pound man with chronic renal failure who is so extremely volume sensitive that hypotension on dialysis and fluid overload off dialysis are constant problems? And this is not to mention an episode of severe cardiac arrhythmias which he once also experienced post dialysis. Yet, this man desperately wants to dialyze at home. Or, if a young man has an intelligence quotient substantially below normal, and his family members do not fare any better, should they be candidates for home dialysis? And what about a man who has lived a long life and is now maintained by dialysis, but becomes reluctant to allow his daughters, or anyone else, to dialyze him? And then there is the more common problem of the man who does not adhere to machine maintenance procedures; does he jeopardize his life on home dialysis?

The Chicago V.A. Research Hospital has encountered such situations in its home hemodialysis program, and any one of them could prohibit continued treatment at home. The case presentations in this report encompass a range of medical, psychological, intellectual, and mechanical difficulties. These cases have been chosen from a patient census of 18 people currently dialyzing at home. There have been a total of 30 patient-assistant teams trained, 9 of whom were transplanted and/or expired, and 3 of whom were transferred. The philosophy behind the home program is that the patient does as much as he is able for himself — the responsibility for the dialysis lies with him, and he should be knowledgeable in all areas of his treatment. And, as has been stated by others,[1] motivation plays an extremely important role — something that is emphasized in all of the following cases:

J.K. is a 55-year-old white male who was in good health until April, 1973, at which time he developed renal failure. Within six weeks of the onset of his illness, he had irreversible renal insufficiency which was demonstrated to be rapidly progressive glomerulonephritis by biopsy. Hemodialysis was initiated on a chronic basis. In Mr. K.'s opinion, the only method of treatment was and is home dialysis. This way enabled him to maintain full-time employment, which to him, for psychological as well as financial reasons, was an absolute necessity. Mr. K., a widower with two grown sons, remarried one year before his illness. Mrs. K. is a highly excitable, anxious individual, which further complicated matters, especially where home dialysis was concerned. And Mr. K., probably due to the rapid onset of his illness, exhibited his denial of it through frequent episodes of fluid overload. True, it did not take much volume to put him into a state of pulmonary edema, nevertheless, he usually admitted his indiscretion — many times prefaced by a statement like "Can't a kidney patient have a little fun?". The consequential shortness of breath greatly agitated his wife. To make matters worse, K. frequently became hypotensive during ultrafiltration on dialysis, which usual-

ly sent K.'s wife into a panic. For these reasons, home dialysis training was prolonged to a total of five months, as opposed to the normal training period of two months. The hypotension problem was fairly much resolved, though not eliminated, by instructing the wife to administer saline if his blood pressure should reach a predetermined level. For most of each dialysis, and for a short period afterwards, Mr. K. remained in a supine position whenever he used high negative pressure. He also had been instructed to rise slowly and to avoid sudden movements during and after dialysis.

In view of the many difficulties in this couple's situation, it was suggested to them by the professional staff that they abandon home dialysis and return to the chronic in-center program. However, Mr. K. saw that as no alternative, but rather as defeat. For him the convenience of home dialysis made it essential, and if they could not continue with home dialysis, he would prefer no dialysis at all. Mrs. K. had a very strong desire to support her husband and backed his decision. So the two of them finally went home, and their dialyses had run a relatively uneventful course, with an occasional volume overload problem and an occasional "panic" problem with some of the more common dialysis difficulties — such as arterial line collapse — for which a calming telephone conversation was all that was required. However, the situation climaxed when they had been at home for a little more than one year. While bathing one night immediately after dialysis, Mr. K. collapsed and appeared to have had a brief episode of cardiopulmonary arrest, probably precipitated by orthostatic hypotension. Mr. K. was resuscitated by firemen and taken to the emergency room of a local hospital where he experienced a definite cardiopulmonary arrest. He was again resuscitated, then placed in the coronary care unit where he was found to have intermittent runs of ventricular tachycardia. The next day he was transferred to V.A. Research, where it was determined that he experienced no enzyme nor electrocardiographic changes to suggest permanent myocardial damage. He was digitalized, dialyzed at the hospital once, and sent home. A dialysis staff member attended the next few dialyses at home to insure that they were uneventful. This episode shook the patient emotionally, but in the long run, it strengthened his wife. She realized his ebbing confidence, bolstered her own, and insisted that they perform dialysis back at home as soon as possible. Chest pain from ribs fractured during resuscitation efforts forced the patient to convalesce at home for one week before he returned to a job for which he had been hired only one month earlier. For the past six months, there have been no further instances of cardiac arrhythmias, and their dialyses have run a much smoother course.

Although most will agree that an individual does not need to be of genius intellect to master home dialysis, the situation becomes debatable if the dialysis candidate has a lower-than-normal intellectual capacity. G.G. is a 27-year-old white male who has chronic renal failure of undetermined etiology. He has had evidence of kidney disease since the age of 19. During the past three years, he has undergone two cadaver transplants, both of which were rejected. Mr. G.'s I.Q. is low. He once had an inclination to learn the repair of washing machines. At that time, he took an aptitude test. The testing service questioned his ability to function in any gainful employment. Simply, there was nothing he seemed suited for. His immediate family consists of his mother and one older sister, neither of whom are much more intelligent than G. So, how does one train such people to dialyze safely and efficiently? A rote method seems to have worked well. Nothing but constant repetition of basic dialysis procedure — setting up the machine, in-

itiating and discontinuing dialysis, handling simple problems — without delving into too much theory. Explanations tend to confuse G.; he simply cannot comprehend. His mother was chosen as the assistant. Actually, she has assumed more of the responsibility then was originally planned, (For example, she and G. alternate setting up for each dialysis.) but G. still manages machine maintenance, that is, sterilizing, cloroxing, cleaning, and lubricating the machines. And he also performs his own venipuncture. He must be reminded occasionally to rotate his sites, but otherwise he does a fine job. Visits to G.'s house are scheduled more frequently than the norm. G. and his mother keep a clinic appointment at the hospital once every six weeks, and occasionally the span between appointments is shorter if there is a specific problem. Telephone communication is frequent. After G.'s last transplant, which was complicated by the development of listeria meningitis, he and his mother were brought in for a two-week refresher course because G. had been off dialysis for approximately five months. Since that time, they have been doing well at home. G. has a lot of determination, and at times he seems determined to go against the normal dialysis procedure — not for spite, for G. is a very affable fellow — but rather because of a twisted conception of his own brand of dialysis theory. For example, there was a period of time when G. refused to use a pressure monitor line in the venous drip bulb. Instead of alerting him to problems in the venous fistula return, G. insisted that the monitor caused the venous needle to "bubble" (infiltrate). Or, he also believed that checking his blood pressure regularly on dialysis "will cause it to drop". But ultimately G. listens to reason, not so much because G. understands the reasoning, but moreso that he seems to believe that the persistence and insistance of the dialysis personnel attaches importance to the particular bit of advice that is being offered.

G. requires constant reinforcement. If he asks a question of a physician, he will not be satisfied with one doctor's response but will instead make the same inquiry of 4 or 5 different physicians.

He has become a champion bowler and is extremely proud of that fact. Everything revolves around bowling, even the acceptance of another cadaver transplant, because the inactivity during convalescence "would throw his game off".

G.'s mother also has a very pleasant personality, and like G., she also sometimes misinterprets dialysis problems, but is always ready to call for guidance. Although the two of them require frequent dialysis counseling, they accept such counseling well, and in view of the odds, are really quite successful with home dialysis.

Another unusual case is that of E.S., a white male who at 83 was found to have decreasing renal function due to prostatic hypertrophy and resulting obstructive uropathy. Although Mr. S. was legally blind from a World War I injury, he was mentally alert, vigorous, and intelligent. He has three devoted daughters, one of whom he lived with. Though his activity was somewhat limited, he kept busy around the house, and managed to do all the cooking for himself and his daughter, in addition to many of the smaller household chores. After months of successful medical management, E.S. had to be started on maintenance dialysis. Because of his extremely poor vision and age, it would have been difficult for him to travel to an in-center program twice weekly. His daughters accepted the responsibility of treating their father's chronic illness; therefore, home training was initiated. Two of his daughters were taught dialysis procedures, and they shared the responsibility equally. After several months,

they began experiencing some difficulty with the arterial flow. Virtually, this was the only problem they encountered during 9 months of dialysis, until E.S. would occasionally become confused. Otherwise, he continued cooking and did household chores. During these periods of confusion, E.S. would sometimes refuse dialysis. The daughters, and occasionally the nurse and doctor, would have to encourage him to be dialyzed. Gradually, he became more adamant, both verbally and physically. Tranquilizing drugs were tried to little avail. Occasionally, a scheduled dialysis was postponed as E.S.'s confused state grew worse, necessitating hospitalization. Shortly thereafter, the patient lost his A.V. fistula. Because of his confused mental state, and his expressed desire to a physician during a lucid period to terminate dialysis, family and staff decided to stop treatment. E.S. lingered for nearly two weeks. During that time, one of his daughters changed her mind and requested that her father be reinstated on dialysis. The surgeons were willing to try creating another A.V. fistula. However, in the interim, Mr. E.S. quietly expired. The family later expressed the thought that what had transpired was for the best, and, at least their father's life had been usefully extended for most of the 11 months he had remained on dialysis.

In a more practical vein, there is perhaps the less isolated problem of lack of adherence to machine maintenance procedure. L.P. is a 43-year-old black male with a history of hypertension and nephrosclerotic kidney disease. He has been on home dialysis for more than two years and, on the whole, does fairly well — with the exception of relatively frequent machine failure. Most times, this can be traced to neglect on his part. An integral portion of the training program consists of teaching routine machine handling. This includes regular replacement of water filters, minor lubrication of moving parts, bleaching, disinfecting with formaldehyde, and basic cleaning of the inside and outside of the dialysis delivery and the water pretreatment systems. Mr. L.P. seems to recall very little of this, although he is a fairly intelligent man. He once ruined the pump on the water pretreatment machine by neglecting to change a pre-filter. And that is an expensive omission! Another time he called to report a machine shutdown — absolutely no water flow. Again, the cause was pinpointed to a filter which had become so clogged that it was creating a complete occlusion. Fairly recently, L.P. phoned to say that the proportioning unit of the delivery system would not work regardless of what he did. Well, it was what he had failed to do that caused the problem. It was badly in need of some lubrication. Since prevention is better than cure, it's obvious that L.P. required technical reinforcement on a regular basis. Home visits by the medical, nursing, and technical staff are, of course, important. But often, these occur while the patient is dialyzing, or when there is an already-existing mechanical problem to be corrected. So, in addition to home visiting, the patient is occasionally brought to the hospital for a day-long technical review.

During the past month, L.P. had occasion for review when he was hospitalized for transplantation. Only a splenectomy was performed. A recent, unexplained, partial obstruction of the urethra precluded kidney transplantation. While convalescing, L.P.'s dialyses were scheduled in the home training unit, where an attempt was made to reinforce proper procedures. Due to his weakness post-operatively, training was limited. In the near future, both Mr. and Mrs. L.P. are scheduled for a brief but intensive refresher course.

By way of summary, the difficulties encountered in four somewhat unusual cases have been described, as well as methods used to deal with them. Three of

the four continue to successfully dialyze at home despite the severity of the problems discussed. In the fourth case, treatment could not be continued because of lack of adequate arterial access for hemodialysis.

REFERENCES

1. Shaldon, S.: Independence in Maintenance Hemodialysis. *The Lancet,* March 9, 1968, pp. 520-523