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## What Went Wrong with Home Hemodialysis in the United States and What Can Be Done Now?

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*In 1973, almost 40% of the more than 10 000 dialysis patients were treated by home hemodialysis. Today, with more than a quarter of a million dialysis patients in the United States, fewer than 2000 are on home hemodialysis. A number of factors have contributed to this change. First, many nephrologists and administrators who were developing new dialysis units had little or no practical experience with dialysis for chronic renal failure. Second, more elderly and diabetic patients were admitted to treatment. Home hemodialysis was more difficult for such patients, and often their helpers were themselves were elderly. Third, hemodialysis machines were difficult to learn and operate. Fourth, following publication of the results of the National Cooperative Dialysis Study, there developed the erroneous concept that a Kt/V equal to 1.0 was “adequate dialysis.” As bigger dialyzers became available, there was a widespread shortening of dialysis time. This decrease in time was embraced by for-profit dialysis facilities and inadequately educated patients, and assembly-line dialysis became generally accepted. Finally, continuous ambulatory peritoneal dialysis, with its simplicity and short training time, began to fill the need of many patients for home dialysis and independence, at least temporarily.*

*Fortunately, the trend is now reversing. Two developments clearly have benefits for home hemodialysis. The first is an increasing interest in the use of more frequent dialysis. The second is the development of new equipment designed specifically for use by the patient, and requiring a minimum of effort on the patient’s part.*

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### Key words

Home hemodialysis, daily hemodialysis, adequacy, Kt/V

### Introduction

Home hemodialysis was pioneered in Boston, London, and Seattle in 1963 and 1964 as a means of providing dialysis to more patients at a time when funding for this treatment was minimal. It proved most successful. In Seattle from 1966 onward, home hemodialysis was the only treatment option offered to patients and, with support from the Washington

State Division of Vocational Rehabilitation and the State Kidney Disease Program, more than 90% of patients were successfully treated at home. Nationwide, by the time the Medicare End-Stage Renal Disease (ESRD) Program began in 1973, almost 40% of the more than 10 000 patients were treated by home hemodialysis. Today, with more than a quarter of a million dialysis patients in the United States, fewer than 2000 are on home hemodialysis [1]. What went wrong?

A number of factors have contributed to this change. First, with almost universal entitlement for treatment under the Medicare ESRD Program, there was rapid growth in the number of new dialysis units, many of which were free-standing and some of which were for-profit dialysis units. This proliferation occurred at a time when clinical nephrology, and particularly the treatment of ESRD by dialysis, was not emphasized and was poorly taught in most U.S. nephrology training programs. Thus, many of the individuals who became the nephrologists and administrators developing the new units had little or no practical experience with dialysis for chronic renal failure. Outpatient hemodialysis units were relatively simple to develop and in-center dialysis simple to provide compared with providing a more complex home hemodialysis training program and its associated support services.

In addition, the initial payment to facilities for outpatient dialysis was very generous while the payment for home hemodialysis was inadequate [2,3]. This was because the Bureau of Health Insurance [now Health Care Financing Administration (HCFA)] did not understand the importance of home hemodialysis. For example, if patients purchased machines, they had to pay the supplier in full immediately, but Medicare only reimbursed 80% of this, and in 24 payments over the next 2 years. Medicare also did not pay the charges for delivery and installation of the equipment. Moreover, home dialysis patients were billed directly by the suppliers for the 20% co-payment, and this had to be paid before delivery of further supplies. Of even greater concern, some of the supplies covered for dialysis in the center were not covered in the home, as they were regarded as not required for “effective operation of a home dialysis machine.” These included such items as syringes, alcohol wipes, tape, bandages, alcohol, povidone-iodine, and underpads.

Of course, in-center patients did not have to deal with suppliers at all. In addition, the cost of on-call nurses and technicians, social workers and nutritionists, and other home hemodialysis costs were not covered. Fees paid to the dialysis facility for home hemodialysis training were insufficient to

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cover the cost of this, and the 3-month waiting period for patients to become Medicare entitled meant that patients generally could not be started on home hemodialysis training until this waiting period was over. By this time, most patients were embedded in a facility. Physicians, too, were not adequately paid for the ongoing management of home hemodialysis patients, and were not paid for supervision of the training of patients. Thus, outpatient dialysis was much more attractive to those establishing new facilities, especially for-profit units, and particularly if they had no experience in home hemodialysis.

During the early years of the Medicare ESRD Program, for-profit dialysis units generally did not provide or support home hemodialysis [3–5]. At a Senate hearing in 1977, representatives of the largest dialysis chain claimed that “the cost of self-care dialysis is not significantly less than limited-care dialysis, and the indiscriminate use of home dialysis may lead to unacceptable patient mortality” [3]. This reluctance of for-profit dialysis units to use home dialysis was illustrated in a report in the *Federal Register* in 1982, showing that, in nonprofit dialysis facilities, 20.4% of patients were treated by home hemodialysis, compared with only 6% of patients in for-profit dialysis units.

The financial disincentives for home hemodialysis were in part resolved by passage of Public Law 95-292 (1978), which included early Medicare entitlement for home hemodialysis training, reimbursement of the facility for home dialysis equipment purchase, and reimbursement for home dialysis at 70% of the outpatient per-dialysis rate. The stated intent of Congress was that “the maximum practical number of patients who are medically, socially, and psychologically suitable candidates for home dialysis or transplantation, should be so treated.” Despite this improvement in reimbursement, the use of home hemodialysis continued to decline. Several years later, the per-dialysis reimbursement for outpatient and home hemodialysis was equalized under a “composite rate.” The hope was that this would serve to encourage greater use of home hemodialysis, but again was without effect.

Several other factors contributed to the decline in use of home hemodialysis over the years. One was the change in the demographics of ESRD patients [1,6]. In 1973, only 3.5% of patients were aged 65 or older, and by 1998 this was 34.4%. Similarly, in 1976, only 7.2% of dialysis patients had diabetic nephropathy, but by 1998 this had risen to 33.2%. These older patients and diabetics had more medical problems and complications, decreased abilities and skills, and fewer social and work-related activities. As a result, home hemodialysis was more difficult for such patients and often their helpers were themselves elderly.

There were contemporaneous changes in society also [7]. Fewer willing dialysis helpers were to be found because of the time involved, changes in family structure, the greater role of women in the workplace, and the increasing emphasis on self. In addition, with the older and sicker dialysis patient

population, fewer patients had adequate support for home dialysis.

Patient concerns included fear of the technical aspects of dialysis in the home and fear of performing self-punctures of their fistulas. There was also concern with the additional time required before and after every dialysis to set up and tear down, and concern about the impact of home dialysis on other family members. In addition, there were changes in patient and family attitudes [7]. At the same time, patients became more passive; these passive attitudes were more likely to be encouraged by busy staff than had been the case in the 1960s. Patients began to develop a lack of acceptance of responsibility for their own health or that of others, and in many cases refused to take any active part in their treatments.

By the early 1980s, following publication of the results of the National Cooperative Dialysis Study [8], there developed the erroneous concept that a  $Kt/V$  equal to 1.0 was “adequate dialysis” [9]. At the same time, disposable dialyzers and larger dialyzers were becoming widely available. In consequence, there was a widespread shortening of dialysis time throughout the country, possibly contributing in part to the poorer survival among U.S. dialysis patients compared with many other countries. Short dialysis was particularly embraced by for-profit dialysis facilities, and this may have been a factor in the poorer survival reported to have occurred in such facilities during the early 1990s [10–12]. Patients themselves also began to demand short dialysis at all costs. Because of inadequate and ineffective education, patients generally came to accept assembly-line dialysis, poor quality of life, and poor rehabilitation.

Because of the decline in the use of home hemodialysis, most nephrologists practicing today have had no experience with patients on this treatment modality. They have not seen firsthand the benefits of improved mortality and quality of life, and many are overly concerned about the safety and the provision of support for these patients. There are now very few dialysis units that can train patients for home hemodialysis, this despite the fact that Medicare regulations still require that all patients be given the option to elect home hemodialysis or transplantation. To establish a new home hemodialysis program requires much more initial effort and ongoing support than to simply expand the number of stations for outpatient dialysis. Also, there continue to be concerns on the part of administrators of the cost effectiveness of home treatment.

Finally, in the late 1970s, continuous ambulatory peritoneal dialysis (PD), with its simplicity and short training time, began to fill the needs of many patients for home dialysis and independence, at least temporarily. This appears to be changing now, with greater use of continuous cycling PD and fewer patients on PD generally [1]. Unfortunately, when PD fails, patients generally do not have the opportunity for home hemodialysis, and so are unable to retain the benefits of home dialysis.

### Benefits of home hemodialysis

The benefits of home hemodialysis are well recognized and have been discussed in detail elsewhere. They include better patient survival [13], better quality of life [14], greater independence, and greater opportunity for rehabilitation [15]. Because dialysis time is not so restrictive, there is more opportunity for adequate dialysis. The convenience of home dialysis and the lack of transportation issues, together with the opportunity for more time with the family and less time around sick people, are all potentially beneficial.

### Steps to reverse the decline in home hemodialysis

Early identification of potential patients for home hemodialysis is essential. Ideally, they can be referred to a home hemodialysis training program and introduced to successful home hemodialysis patients and their families before they have to start treatment. Early blood access placement also facilitates earlier start of training.

### What will happen to home hemodialysis in the future?

There have been two developments clearly beneficial to home hemodialysis. The first is the increasing interest in the use of more-frequent dialysis. "Daily" hemodialysis generally means 5 – 7 treatments per week, and this can be carried out either as short daily dialysis in a unit or at home for 1.5 – 2.5 hours, or long overnight (nocturnal) dialysis for 6 – 10 hours while sleeping, again typically performed in the home [16–19]. Benefits include reduction in hospitalizations, medications, acute symptoms during and following dialysis, and fistula complications, together with improvement in toleration of dialysis, control of hypertension, anemia, and erythropoietin dosage, and cardiovascular and nutritional status [16–19]. In addition, quality-of-life benefits have been recorded, including improvements in mental clarity, sexual function, sleep, energy and strength, and rehabilitation, together with reductions in thirst, pruritus, dietary restrictions, restless leg syndrome, fatigue, and depression [16–19].

The second is the development of new equipment designed to allow more-frequent dialysis, to be used by the patient, and to require the minimum of effort on the patient's part [20]. Several programs are now reporting on more-frequent dialysis, either overnight or in-center, using modifications of contemporary equipment.

### Future policy issues that may affect home hemodialysis

First are work force issues: The continuing growth in the incidence and prevalence of ESRD patients in the U.S. and elsewhere, the changing patient population, with more elderly and diabetic patients, and the developing shortage of nephrologists and dialysis nurses have to be confronted. Undoubtedly, nurses and technicians will play an increasing role in the provision of routine dialysis services. Patients too can obviously play their part in this. There will be continuing growth in the number of dialysis units, but even so, if the

number of patients doubles in the next 10 years, one form of relief will be to encourage more home hemodialysis.

The most important issue is the improvement of quality of care for dialysis patients. The past 10 years have seen concern in the U.S. with respect to mortality. This and other clinical problems have been addressed by the HCFA Core Indicators Project [21] and by developments such as the Dialysis Outcomes Quality Initiative (DOQI) guidelines [22]. However, too often, physicians have not had sufficient time or interest to ensure the best quality of life for patients. This is where more frequent dialysis comes in. All reports on this issue have been uniform in describing the benefits. Those of us who have seen and treated patients in this way are struck by the fact that they come to look like normal people. Some patients have taken themselves off the transplant list because they feel so well, and others have threatened to stop dialysis if they have to return to three-times-weekly dialysis.

A new era in dialysis treatment is beginning. We all need to make efforts to ensure that quotidian home hemodialysis is made widely available so that as many patients as possible can benefit.

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