The End-Stage Renal Disease Program

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By the mid 1960s it had been clearly demonstrated that the lives of people with total, permanent kidney failure could be indefinitely prolonged with the artificial kidney and that an acceptable proportion of kidney transplants would be successful. The extraordinary cost of this form of therapy, however, prohibited its application to the majority of patients. A strong lobby of health care providers and consumers sought government assistance and in the spring of 1972 Congress passed Public Law 92-603 (Section 2991) which provided for payment of 80% of costs for management of end-stage renal disease (ESRD) for all persons eligible for Social Security benefits, regardless of their ability to pay. This law established what is, in effect, a national health insurance program for people with end-stage renal disease and it may well be a model for future national health insurance programs.

Until early 1977, the ESRD program was administered through the Bureau of Health Insurance of the Social Security Administration and the Bureau of Quality Assurance of the Public Health Service; after that the responsibility for all administrative activity was consolidated in the newly formed Health Care Financing Administration (HICFA).\(^1\) Primary responsibility for medical matters was assigned to the Health Standards and Quality Bureau and fiscal matters to the Medicare Bureau.

To facilitate administration at the local level, the nation was divided into 32 ESRD networks by the Secretary of Health, Education and Welfare according to established referral patterns, modalities of services offered, and population (Fig 1).\(^2\) The network boundaries do not necessarily follow state or other government lines. Virginia is divided among three networks. The large central portion of the state and the whole of West Virginia make up Network 30. The Virginia counties of Scott and Washington are in Network 18 with Tennessee, Alabama, and Mississippi. Four northern Virginia counties, Arlington, Fairfax, Loudoun, and Prince William, have been included in Network 23 with the District of Columbia and five Maryland counties. This division of Virginia was considered consistent with established referral patterns and medical communications; funding for the establishment of these networks was made available in August 1977, and all of them are now active. Network 30 was organized in 1977 as a free-standing, non-profit corporation called the ESRD Network Coordinating Council of the Virginias, with offices in Richmond.

The governing body of the network is the Network Coordinating Council (NCC). Federal regulations require that each approved ESRD care facility provide a representative to this body and that all health care disciplines concerned with ESRD be represented including physicians, nurses, social workers, dietitians, technicians, and administrators. Consumers must also be represented but not as a majority.

The objective of the network is to assure that all persons with ESRD have access to appropriate care. The coordinating council is concerned with monitoring the quality of care and encouraging the appropriate distribution and utilization of ESRD care facilities. To avoid duplication of effort and conflict of interest, working agreements are being developed between the networks and other agencies with similar objectives including Professional Standards Review Organizations (PSRO) and Health Systems Agencies (HSA).
Each network is required to have a Medical Review Board (MRB) to supervise the appropriateness and quality of care of ESRD patients. The Medical Review Board is appointed by the NCC and consists of a nephrologist, transplant surgeon, registered nurse, social worker, and three additional physicians. Standards of care are recommended by the MRB for approval by the NCC. It is expected that this procedure will allow the establishment of high standards of care acceptable to all health care providers. Compliance is voluntary and the NCC has no powers of enforcement. The Network 30 MRB is completing the first medical audit of dialysis patients, and an ongoing review program is planned that will consider all aspects of ESRD patient care.

The distribution and utilization of medical care facilities have recently been the subjects of considerable discussion and government attention at all levels; the ESRD program is no exception. The authorizing legislation requires the establishment of minimal utilization rates of both dialysis and trans-
ANNUAL PROJECTED COSTS OF MEDICAL SERVICES*
MEDICARE DIALYSIS AND TRANSPLANT PATIENTS
UNITED STATES, 1974-1984**

Cost in Million Dollars

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*Projections are based only on those inpatient and outpatient services covered by Medicare as of December 1977.

**Calendar year.

Fig 3—Projected costs of the ESRD program. Estimates provided by the Health Care Financing Administration, Office of Financial and Actuarial Analysis—Medicare.

Plant facilities. These rates have now been established and all facilities must be in compliance to receive payment for services. The NCC has no authority to regulate utilization or distribution of facilities, but it is expected that it will provide consultation to HSAs and state health departments in these matters.

A national End-Stage Renal Disease Medical Information System (ESRD MIS) is being developed to collect data on the types of facilities and services provided and on the course of illness of patients with ESRD. It is anticipated that the data generated will provide basic information to assess and evaluate the quality of care provided to ESRD patients and the type of information needed for effective health care delivery planning. This system replaced the Human Renal Transplant Registry and the National Dialysis...
Registry. Unfortunately, this new system has been slow in starting and only limited data regarding ESRD patients have been published since the other registries ceased operation in 1976.

As expected, the number of patients receiving ESRD care has rapidly increased since 1972. According to the National Dialysis Registry, there were only 2,426 patients receiving dialysis in the United States in 1970. By June 1977 the Social Security Administration estimated that 33,371 persons were receiving dialysis treatment in over 800 facilities under the ESRD programs. Transplantation activity has increased also but not quite so rapidly. The growth of dialysis and transplant activity in Virginia has generally paralleled that of the nation (Fig 2). There are approximately 27 dialysis facilities and 4 transplant programs [University of Virginia, Medical College of Virginia, VA Hospital (Richmond), Eastern Virginia Medical School] in this state. The basic needs of the patient population are being met. There remain, however, some areas where the distance to a facility is unacceptably long. This is particularly true in the south central and southwestern portions of the state, but it is expected that units will soon be organized in these poorly covered areas. Considerable effort is being made to increase transplant activity, particularly by improving cadaver organ procurement.

The ultimate size of the ESRD program is difficult to predict. It has been estimated that 50-75 new ESRD patients per million population per year will be candidates for treatment. This may well be a low estimate, since practically all patients are now considered candidates for some form of treatment. The Social Security Administration predicts 55,900 patients will be receiving treatment by 1982.

The cost of this program is staggering. According to the most recent projections, expenditures for 1978 will approach $1.0 billion and will be $3.0 billion annually by 1984 (Fig 3). The cost of maintaining a chronic dialysis patient who receives dialysis in a center approaches $25,000 per year. A saving of $8,000 to $10,000 annually is realized if the same patient performs self-dialysis at home. The cost of a successful transplant is approximately $25,000 the first year and $1,000 to $3,000 each year thereafter. It is very likely that legislation will be passed in 1978 that will provide incentives for both health care providers and consumers to employ the less expensive alternatives. Changes in reimbursement procedures are also expected. These measures will help, but important changes in the artificial kidney and considerable improvement in transplant results will be required before major cost reductions are possible.

In summary, a national health insurance program for people with permanent failure of one organ system is well established. Appropriate care for most Americans with ESRD is readily available and affordable. The program, though effective and growing rapidly, is extremely expensive and cost containment is the major concern of health care providers and the government. The mechanism of administration of this program may well be the model for future national health insurance programs.

Figures 1 and 3 are reproduced by permission from the US Department of Health, Education and Welfare.

Figure 2 is abstracted from The Renal Program of Virginia 1977.

REFERENCES