

**Chapter 7**

**Dialysis for  
Chronic Renal Failure**

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# Dialysis for Chronic Renal Failure<sup>1</sup>

## INTRODUCTION

Individuals with end-stage renal disease (ESRD) would die within a few weeks or months if not sustained by some form of dialysis therapy or a kidney transplant. Nearly 91,000 Americans currently receive some form of dialysis (43). As recently as the 1960s, the scarcity and high cost of resources made treatment of chronic renal failure largely unavailable and inaccessible. Treatment was limited to the affluent and the hand-picked. So-called "God committees" composed of health professionals and community leaders selected patients on the basis of criteria that included age, race, sex, family responsibilities, employment and financial status, and "social worth." Patients younger than 15 or older than 45 were routinely disqualified for treatment.

The Federal Government's commitment in 1972 to cover the catastrophic cost of treatment for ESRD through Medicare was a pivotal event that has remained a touchstone in subsequent debates about providing expensive medical care for specific groups of patients. Medicare's ESRD program, enacted into law (Public Law 92-603, Sec. 2991) in 1972 and initiated in 1973, is the only Federal program that provides almost complete coverage for a catastrophic illness (5). It is at once a forceful reminder of the problems that may exist without Federal intervention and of the problems that may arise *as a result* of intervention.

Largely as a result of the ESRD program, dialysis and renal transplantation are now available to virtually all Americans in need, without regard to age, social status, or ability to pay. Following the program's implementation, there occurred rapid expansion of treatment facilities and personnel and significant advances in dialysis and transplantation technologies (25). Not surprisingly, the number of patients being treated for ESRD

increased dramatically. Today, the old problem of access to ESRD treatment has been replaced by one of tremendous public cost. The current cost of providing benefits to ESRD Medicare beneficiaries is about \$2.1 billion per year and growing (41).

People over age 65 are now the fastest growing segment of the dialysis population served by Medicare's ESRD program, with an average annual growth rate of 15 percent in recent years (40). In 1974, people over 65 who were eligible for ESRD benefits by virtue of Medicare enrollment made up less than 5 percent of the average annual enrollment (5); by 1979, patients over 65 accounted for over 20 percent and by 1984, patients over 65 accounted for over 25 percent of Medicare's ESRD program enrollees (40).

The unanticipated growth in ESRD program expenditures and the shifting demographic composition of the dialysis population have heightened concerns among some people that dialysis is being overused, that is, public resources are being misallocated, and/or dialysis treatment is being wasted on some patients for whom the benefits are questionable. The U.S. experience with dialysis is frequently cited by those who wish to warn against excessive growth in other disease-specific benefit programs or overuse of other life-sustaining technologies.

Because dialysis is usually life-sustaining, available, and currently reimbursed through Medicare's ESRD program, the dilemmas about whether to use dialysis in individual patients often center around the impact treatment would have on the patient's quality of life. Chronic dialysis imposes a strict regimen that demands time, limits travel, and imposes strict dietary requirements. Complications and frequent periods of illness and hospitalization are common. Still, most patients who accept chronic dialysis adjust successfully and are able to carry on their family and work

<sup>1</sup>OTA acknowledges the important contribution in the preparation of this chapter of Nancy B. Cummings, M. D., Associate Director for Research and Assessment, National Institute of Diabetes, Digestive and Kidney Diseases.

roles. Some dialysis patients have survived for more than 20 years.

Only limited information is available about how elderly patients adjust to chronic dialysis. However, the greater likelihood that elderly people will have comorbidities or reduced social responsibilities, compared with younger people, suggests that there may be important age-related differences in elderly patients' physiological and psychosocial responses to chronic dialysis. One study found that older patients generally reported a high degree of life satisfaction while undergoing chronic dialysis (49). Another study found, however, that withdrawal from dialysis was the most common cause of death in elderly dialysis patients, accounting for 40 percent of all deaths (compared with 22 percent for all ages) (16). The high rate of dis-

continuation may occur because the factors that trigger the decision, such as multiple underlying diseases, are more common and occur earlier in older dialysis patients than in younger ones (16).

While problems of access to ESRD treatment and personal financial hardship have been addressed to a very great extent through Medicare's ESRD program, fundamental problems related to decisionmaking for individual patients and related concerns remain. This chapter examines ESRD in the elderly population, the use, cost, and efficacy of various types of dialysis, the patients' experience, and how treatment decisions are made. It also discusses patient selection criteria and the influence of reimbursement on treatment patterns and quality of care for elderly patients.

## DESCRIPTION OF DIALYSIS

### ***Renal Failure: The Need for Treatment***

Healthy kidneys regulate the body's internal environment of water and salts and excrete the end products of the body's metabolic activities and excess water (as urine). They also produce and release into the bloodstream hormones that regulate vital functions including blood pressure, red blood cell production, and calcium and phosphorus metabolism.

Impaired renal function, depending on its cause and severity, may affect any or all of these processes (see table 7-1). Impaired renal function may be due to problems in the kidney or to disease in other organs. It may be caused by pathological problems or normal, age-related processes.<sup>1</sup> It may be acute or chronic and either minor or life-threatening. All these distinctions are important

determinants of prognosis and appropriate treatment.

When a person's loss of renal function is so severe as to be incompatible with life, the patient is said to be in renal **failure**. Renal failure may be either acute or chronic.

**Acute renal failure** is the sudden, potentially reversible loss of renal function. It may be caused by any of several hundred diseases, by drugs that are toxic to the kidneys, surgery, trauma, reduction or cessation of blood flow (i.e., ischemia) to the kidneys, or by obstruction of urine flow (13, 22). Many patients in acute renal failure regain natural function of the kidney after temporary support by dialysis. Others die from the underlying disorder that caused the kidney to fail. In some patients, acute renal failure is the precursor to chronic renal failure.

**Chronic renal failure** is irreversible, often progressive loss of kidney function. It can be caused by any of a large number of known and unknown factors, including immunological, congenital, or infectious diseases, or trauma to the kidneys. By far the most common cause of chronic renal failure among elderly dialysis patients in Medicare's ESRD program is hypertension (with heart and renal diseases). Other less common

<sup>1</sup>Normal aging, in the absence of disease, is associated with a progressive loss of renal function beginning early in adulthood. On average, adults lose 7 to 8 percent of renal function per decade, but the individual variability in age-associated loss of renal function is very great. Some people lose as much as 60 to 70 percent between the ages of 30 and 80, and others experience little or no age-associated loss of renal function. Even when extreme, the normal changes in kidney function associated with aging do not significantly interfere with the normal volume and composition of body fluids or normal levels of waste products. Normal, age-related changes in renal function are significant, in general, because elderly individuals have lower reserve and are at heightened risk for developing renal failure as a result of disease or injury.

Table 7-1.—Functions of the Kidney and Their Alteration in Chronic Renal Failure

Function	Change in chronic renal failure
Excretion of water . . . . .	Well-preserved in early chronic renal failure, progressively reduced in late chronic renal failure.
Excretion of water-soluble compounds . . . . .	Varies with the compound; in general, progressively reduced as chronic renal failure progresses.
Production of erythropoietin (stimulates red blood cell formation) . . . . .	Progressively reduced but not usually to zero; moderate to severe anemia.
Production of 1.25- and 24.25-hydroxycholecalciferol, the active forms of vitamin D . . .	Reduced in moderate to severe chronic renal failure—reduced blood calcium and tendency to bone disease.
Production of renin—hormone which helps to maintain blood pressure and conserve sodium. . . . .	Often increased—contributes to high blood pressure of chronic kidney disease; removal of both kidneys (to cure this) may cause low blood pressure,
Production of prostaglandins and intrarenal hormones . . . . .	Uncertain what part changes in secretion of such hormones play in producing the symptoms of acute and chronic renal failure.

SOURCE, D N S. Kerr, "Renal Dialysis: Techniques and Clinical Applications," *The Oxford Companion to Medicine*, J. Walton, P.B. Beeson, and R.B. Scott (eds.) (Oxford, England: Oxford University Press, 1986)

causes of chronic renal failure in elderly people are glomerulonephritis, diabetic nephropathy, polycystic kidney disease, and pyelonephritis (1).

As defined in Medicare regulations, ESRD is the "stage of chronic renal impairment that appears irreversible and permanent, and requires a regular course of dialysis or kidney transplantation to maintain life" (4). ESRD, with an accompanying syndrome called *uremia* (i.e., the symptomatic phase of renal failure), affects almost every system of the body, including the cardiovascular, respiratory, endocrine, central and peripheral nervous systems, the gastrointestinal tract, blood cells, skin, and bones. The symptoms often are so general that a diagnosis of kidney disease may not be clear. People experience an overall sense of feeling poorly, and they may have difficulty pinpointing the source of their malaise. The scientific understanding of all the ramifications of disorders of the kidneys is limited.

Disordered kidney function may be detected by simple laboratory tests such as urinalysis, measurement of blood chemistries (urea, creatinine, electrolytes, calcium, and phosphorus), and by determining the kidney's ability to clear standard substances from the blood.

### ***Dialysis Procedures***

ESRD can be managed by renal dialysis or reversed by a successful kidney transplant from a living or cadaveric donor (23). In special cases,

other newer technologies such as hemoperfusion, hemofiltration, hemodiafiltration, and plasmapheresis may be used (1) (also see app. C, "Future Developments in Life-Sustaining Technologies").

For some patients, ***kidney transplantation*** is the preferred treatment. A successful kidney transplant can restore a patient to good health and a nearly normal lifestyle. The best results are obtained when the organ donor is a living, related donor, although good success is also achieved with cadaver kidneys.

Unfortunately, while transplantation is an attractive solution in principle, there are many difficulties in its implementation, especially the severe shortage of appropriately matched donor



Photo credit Edmund G Lowrie, National Medical Care, Inc

This 83-year-old woman has been on dialysis for 5 years.

kidneys (25). In addition, life-long immunosuppressive therapy, necessary to prevent rejection of the donor organ, has many deleterious effects. Because of these and other problems, kidney transplantation is not at present a realistic option for most ESRD patients. In 1985, only 9 percent of all ESRD patients received a transplant (42).

Kidney transplants are seldom performed in elderly people. In 1985, only 56 (1 percent) of the 6,938 kidney transplants performed in the United States were performed in patients aged 65 to 74 years, and only 3 were performed in patients 75 years and older (46). This apparent age-based rationing of kidney transplantation is usually explained on medical grounds. In particular, persons with vascular diseases (e.g., arteriosclerosis) are considered poor candidates for transplant surgery, and vascular diseases are common among elderly persons (13). Another medical factor that weighs against performing kidney transplants in some elderly persons is that they have multiple illnesses, which increase the risk of serious complications. Another serious problem is that age-related and other decreases in immune function heighten the risk of infection, especially with the administration of immunosuppressive agents that must be used to prevent rejection of the transplanted kidney.

How many elderly people might benefit from kidney transplantation if more donor kidneys were available is not known. At present, however, **renal dialysis** is the only widely used ESRD treatment for elderly persons. Therefore, renal dialysis is the focus of this chapter.

The term dialysis refers to any process in which the components of a liquid or solution are separated on the basis of the selective movement of different kinds of molecules through a semipermeable membrane. In the case of renal dialysis, impurities are separated from the blood and passed into a special fluid called the "dialysate" (or dialysis fluid) through a natural or artificial membrane. The movement of molecules through the membrane is caused by differences in concentrations of salts and toxic waste products in the blood and in the dialysate. Contact between the blood and dialysate is repeated many times, and the transfer continues until the two solutions have identical concentrations of the affected substances.

Other components of the blood, like proteins and cells, cannot pass through the membrane and are retained in the blood.

The effectiveness of dialysis depends on both its duration and efficiency. The dialysis fluid, which is made up of the physiologically normal electrolytes found in blood plasma, is selected according to the approximate eventual composition desired in the plasma. When dialysis proceeds too rapidly, it may cause symptoms such as painful cramps or problems with blood volume. Because the specific treatment is determined based on experimentation, rather than theoretical knowledge, dialysis is said to be an "empirical" therapy.

Dialysis offers an effective artificial mechanism for performing kidney functions. Two main types of dialysis are available: 1) hemodialysis, and 2) peritoneal dialysis (including several variants of the latter).

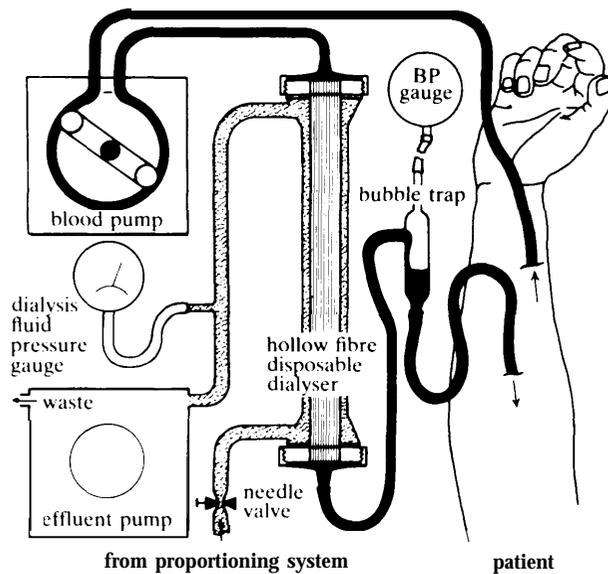
### Hemodialysis

Hemodialysis is the oldest, most prevalent method of dialysis, and it is used today by the vast majority of ESRD patients in this country. It is the standard against which newer methods are judged. The first hemodialysis machine was developed in the Netherlands by Wilhelm Kolff during World War II. This "artificial kidney" and modifications of it permitted the first successful attempts to sustain patients with acute renal failure (1). Not until the 1960s, however, were there hemodialysis procedures to allow long-term **maintenance dialysis** of patients with chronic renal failure (1).

The process of hemodialysis involves pumping blood out of a patient's body into a dialyzer where impurities are removed, then returning the blood to the patient's body (see figure 7-1). For most ESRD patients using hemodialysis, treatments are carried out three times weekly for a duration of 3 to 5 hours each time. Some patients require more frequent hemodialysis, while some patients with significant residual kidney function can manage on fewer treatments per week. Hemodialysis may be conducted in a hospital, freestanding dialysis center, or in the patient's home.

Originally, hemodialysis required a new arterial and venous cut-down to obtain access to the patient's bloodstream for each dialysis treatment.

Figure 7-1.—Hemodialysis

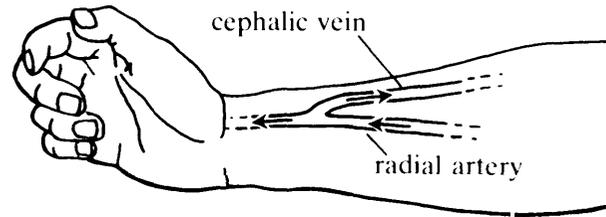


Blood is taken from the arterial tube and pumped through the hollow-fiber disposable dialyzer before returning through an air trap to the patient. Dialysis fluid flows in the opposite direction from a proportionating system, which makes it from water and concentrate. A number of safety devices (not shown) monitor the temperature, flow, and pressure of the dialysis fluid and the presence of air bubbles in the blood stream.

SOURCE: D.N.S. Kerr, "Renal Dialysis: Techniques and Clinical Applications," *The Oxford Companion to Medicine*, J. Walton, P.B. Beeson, and R.B. Scott (eds.) (Oxford, England: Oxford University Press, © 1988).

The use of maintenance hemodialysis for patients with chronic renal failure was not possible until a Teflon arteriovenous shunt was developed by Scribner and his coworkers at the University of Washington in the early 1960s (1). Today, the standard blood access system for hemodialysis involves a surgically created connection between an artery and vein known as an arteriovenous fistula (see figure 7-2). Access to the fistula, which is usually in the forearm, is obtained by needle puncture. Developed in 1966, the arteriovenous fistula resolved problems that plagued patients with the arteriovenous shunt (i.e., clotting and infection) and offers a more permanent solution. Subsequent developments and refinements in the fistula have resulted in shorter dialysis time, increased safety, greater comfort, and economy. For patients whose veins do not permit the creation of a fistula, a variety of grafts are now possible; however, the "native" arteriovenous fistula is con-

Figure 7-2.—Arteriovenous Fistula in the Arm of a Hemodialysis Patient



Arterial blood flows through the surgically created fistula into a superficial vein into which needles are inserted in the approximate direction of the arrow, identifying the cephalic vein.

SOURCE: D.N.S. Kerr, "Renal Dialysis: Techniques and Clinical Applications," *The Oxford Companion to Medicine*, J. Walton, P.B. Beeson, and R.B. Scott (eds.) (Oxford, England: Oxford University Press, © 1986)

sidered "the gold standard of blood access" (1). Consequently, one of the most important measures in the management of patients with chronic renal failure before they require dialysis is to preserve the forearm vessels so these can be used to develop a fistula when required (32).

Dialyzers consist of three parts: a compartment for the blood, a compartment for the dialysate, and a semipermeable membrane separating the two (30). The three principal types of dialyzers—hollow fiber, coil, and parallel plate—differ essentially in how these basic parts are arranged (30). All three types are described by manufacturers as "single-use disposable," but in fact are often reused (30). This practice of reprocessing and reuse, possible since the 1960s, has become widespread, but it remains controversial.<sup>3</sup>

Dialysate is usually prepared by diluting a commercially available concentrate with treated tap water. The specific composition of the dialysate reflects the needs of the individual patient and the choice of the physician.

<sup>3</sup>In the late 1970s, there was a strong patient movement against dialyzer reuse in the United States, and the Senate Special Committee on Aging held hearings on the subject and produced a staff report on the subject (38). The effect of Federal policies on the practice of dialyzer reuse was reviewed in an OTA case study (30). Reuse is now very widely practiced worldwide (1). Under the 1987 budget reconciliation, the U.S. Department of Health and Human Services must establish, by Oct. 1, 1987, standards and conditions for safe and effective reuse and reprocessing of dialyzers (37).

## Peritoneal Dialysis

The second major form of renal dialysis is peritoneal dialysis. First applied successfully in the treatment of acute renal failure in the late 1940s, peritoneal dialysis is a relatively simple technique whose use has increased for both chronic and acute care since the mid-1960s (1).

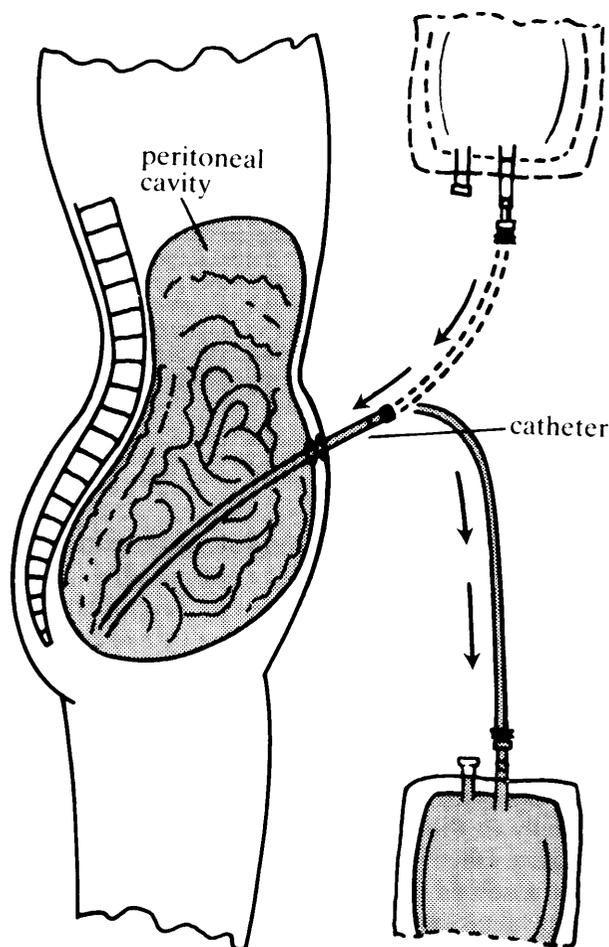
Peritoneal dialysis uses the patient's peritoneum (the semipermeable membrane surrounding the abdominal organs and lining of the abdominal cavity) to perform dialysis inside the patient's body. The standard blood access device is a permanent indwelling catheter with a long subcutaneous tract placed in the patient's abdomen. Sterile, warmed dialysis fluid is infused via the catheter into the patient's peritoneal cavity, allowed to remain there the prescribed length of time, then drained out along with the dissolved waste products, discarded, and replaced with fresh fluid. This cyclical process is continued for the appropriate number of instillations and removals. Solute removal occurs by diffusion from the blood in the peritoneal capillaries to the dialyzing solution. Solute removal depends on factors such as the dialysate flow rate, temperature, and pH. Fluid removal is by osmosis (1). Although peritoneal dialysis is much slower than hemodialysis, the same degree of correction occurs provided that longer peritoneal treatments are used.

Depending on the locale and timing of the procedure, chronic peritoneal dialysis may be intermittent (IPD); continuous cycling (CCPD); or continuous ambulatory (CAPD). Continuous peritoneal dialysis methods are typically used in the patient's home, while intermittent peritoneal dialysis is usually performed in a center or hospital.

Intermittent peritoneal dialysis involves the use of a machine to deliver sterile dialysate to the patient's peritoneal cavity and, after the prescribed dwell time, to remove the spent dialysate. The equipment is based on either a cyclor that operates by gravity, a pump, or, in older equipment, a reverse osmosis process. Intermittent peritoneal dialysis is usually carried out for 10 to 12 hours, 3 nights weekly. The main problem with this technique is that as a patient's residual renal function declines, he or she requires longer treatment times.

CAPD, a technique of portable self dialysis introduced in 1976, affords patients relative freedom and control over their own care, because it requires no machine and, often, no assistance (see figure 7-3). Self-care CAPD patients empty a 2-liter bag of dialysate into their peritoneal cavity and then proceed with their usual activities for the next 4 to 8 hours or overnight. At the end of the dwell time, the dialysate is drained into the empty bag, detached, and replaced by a fresh bag. The

Figure 7-3.—Continuous Ambulatory Peritoneal Dialysis (CAPD)



A sealed bag containing 2 liters of dialysis fluid is first emptied into the peritoneal cavity, then wrapped up and stowed in a pouch while the patient walks around, and finally hung below the abdomen to drain out the used fluid. The old bag is then changed for a full new one.

SOURCE: D.N.S. Kerr, "Renal Dialysis: Techniques and Clinical Applications," *The Oxford Companion to Medicine*, J. Walton, P.B. Beeson, and R.B. Scott (eds.) (Oxford, England: Oxford University Press, © 1986).

process of drainage, disconnection, connection, and infusion takes 30 to 45 minutes. The process is repeated three to five times daily, 7 days a week. Sterile technique must be maintained. CAPD has undergone an astonishingly rapid increase in use worldwide. It is now the most popular form of peritoneal dialysis and the most common form of home dialysis, accounting for over 13 percent of all dialysis patients in the United States (46). Apart from possible complications, one main problem with CAPD is that the patient has little or no respite from continuous treatment,

CCPD is a combination of intermittent peritoneal dialysis and CAPD that involves the use of a machine to cycle dialysate in and out of the peritoneal cavity automatically overnight and ambulatory peritoneal dialysis during the day (6). Typically, the dialysate is instilled into the peritoneal cavity in the morning and remains there until connection to the dialysis machine in the evening. CCPD reduces the need to make bag changes during the day and, by reducing the number of connections to a machine, may also lessen the risk of peritonitis (inflammation of the peritoneum).

### ***Treatment Settings***

The choice of treatment setting is closely related to the type of renal dialysis to be used. Both setting and type of dialysis depend on the patient's medical condition, ability to participate in care, level of support that the patient has available at home, resources in the community, and patient and caregiver preferences. Patients in acute renal failure are treated in hospital inpatient facilities, often in an intensive care unit (ICU). Patients with chronic renal failure can be treated in an ICU or a hospital inpatient facility, but if they are medically stable, they can receive dialysis in an outpatient facility (either a hospital-based outpatient unit or a freestanding dialysis center) or at home (1).

Institutions that provide outpatient dialysis for patients with chronic renal failure are divided by Medicare's ESRD program into two categories: hospital outpatient units and freestanding dialysis centers (1). Hospital outpatient dialysis units use the existing administrative structure of the hospital and are able to offer the usual range of

hospital services, including diagnostic, therapeutic, and rehabilitative services. Freestanding dialysis centers provide staff-assisted outpatient dialysis but do not provide inpatient services (such centers usually contract with hospitals for necessary inpatient hospital services). More than 58 percent of the 1,558 institutions approved to provide outpatient chronic dialysis services in the United States are freestanding facilities (45).

Home dialysis involves training the patient and a family member, or in some cases a paid dialysis helper when a family member is not available, in order to assist the patient with dialysis at home (3). Home hemodialysis training takes from 3 weeks to 3 months, and home peritoneal dialysis training takes 1 to 2 weeks (1). Home dialysis gives patients with chronic renal failure a measure of independence and often reduces the cost of personnel (1). In general, however, home dialysis requires more patient initiative, responsibility, and better health. Home dialysis patients, because they are relatively healthy, have fewer hospitalizations than other dialysis patients and their annual total costs tend to be lower (39).

Home dialysis requires a range of support services on an ongoing basis. The patient should receive regular medical followup from a physician (usually monthly). Arrangements must be made for provision of supplies and maintenance and repair of equipment. Ongoing social work support, vocational rehabilitation services, and nutrition counseling are also important. The patient also must have contacts with appropriate members of a dialysis unit in case of an emergency. A nurse should be available on call at all times to answer questions or to respond in an emergency. In addition, self-care patients and their family members must be prepared for medical or mechanical emergencies.

### ***Choice of ESRD Treatment Modality***

In general, the least restrictive ESRD treatment modality that is medically appropriate should be the first choice. Thus, a chronic renal failure patient who is medically stable, instead of being confined to the hospital as an inpatient, should probably receive maintenance dialysis at a freestanding dialysis center or hospital outpatient unit. Simi-

larly, a patient capable of home dialysis should be allowed that option because of the greater freedom it permits. Home dialysis places great responsibility on the patient. This is especially true for CAPD, which requires that the patient perform four or five treatments daily with meticulous attention to sterile technique (34).

Sometimes decisions about ESRD treatment modalities are limited by the availability of resources. Kidney transplantation, for example, depends on the availability of a living, related donor or cadaver kidney. Given the present shortage of donor kidneys, transplantation is not always an available option.

## UTILIZATION AND COST OF DIALYSIS

### *Utilization of Dialysis*

Medicare's ESRD program covers 93 percent of all patients with chronic renal failure in the United States (9),<sup>4</sup> and has made treatment for ESRD available to an increasing number of elderly and other Americans (see table 7-2).

In 1985, Medicare's ESRD program served a total of 90,621 dialysis patients and there were 6,938 transplants (46).<sup>56</sup> Almost 31 percent of all dialysis patients in the Medicare ESRD program were over the age of 65 (46). Virtually all ESRD patients who are elderly when treatment is initiated are on dialysis.

The percentage of new dialysis patients who are elderly has increased faster than any other age group, with annual percentage increases from

<sup>4</sup>Persons covered by the armed services or by certain State or private insurance programs are exceptions (35).

The total number of ESRD patients is not equal to the number of transplant patients plus the number of dialysis patients because dialysis patients may receive a transplant, a patient may receive more than one transplant, and a transplant patient may be returned to dialysis if the graft fails.

<sup>56</sup>The Veterans Administration, which has a high proportion of elderly male patients, had 3,327 dialysis patients in 1985 (40).

1980 to 1984 of 11.7 percent for patients age 65 to 74 and 20.7 percent for patients over 75 (40). As evidence has accumulated that many elderly patients tolerate dialysis well and have a reasonable quality of life, more physicians recommend the therapy and more patients are willing to try it.

While elderly patients are undergoing dialysis in increasing numbers, they have not received treatment at the same rate as younger people. In 1979, while 80 percent of the patients age 25 to 45 at risk to die of uremia entered dialysis, only 30 percent of patients at risk over age 65 and just 6 percent of patients over age 75 did so (16).

The proportion of elderly ESRD dialysis patients will probably continue to increase for sometime. This prediction is based on the aging of the U.S. population and the expectation that cadaver kidneys will become more readily available to younger ESRD patients (1).

One important implication of the increased enrollment of elderly persons in Medicare's ESRD program is an increasing proportion of patients with vascular and other comorbid conditions. Such conditions increase morbidity and reduce

Table 7-2.—Medicare ESRD Program Enrollment by Age, 1979-84

	1979	1980	1981	1982	1983	1984	Average annual percent increase	1983-84 percent increase
Total . . . . .	54,428	61,899	70,435	77,886	86,499	92,770	11.3	7.2
<b>Age:</b>								
Under 25 years . . . . .	4,145	4,552	5,023	5,406	5,817	6,025	7.8	3.6
25 to 44 years . . . . .	15,325	17,108	19,745	21,694	24,070	26,070	11.2	8.3
45 to 64 years . . . . .	23,561	26,351	29,844	32,773	35,330	36,991	9.4	4.7
65 years or over . . . . .	11,397	13,688	15,823	18,013	21,282	23,684	15.8	11.3

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, Bureau of Data Management and Strategy, *Research Report: End-Stage Renal Disease, 1985* (Washington, DC: U.S. Government Printing Office, in press, 1987).

survival among patients receiving dialysis. Furthermore, since patients with such conditions are more likely to be hospitalized than patients without such conditions, their per capita costs are likely to be higher. It is uncertain whether all the patients with diabetic ESRD and all the elderly patients who might benefit from dialysis are being referred.

Growth in the overall U.S. ESRD dialysis population between 1980 and 1984, is shown in table 7-3. Growth in the overall population averaged approximately 10 percent per year. Growth in the number of patients using CAPD averaged almost 37 percent per year.

### ***Cost of Medicare's ESRD Program***

The economic burden of dialysis and kidney transplantation is great for the U.S. health care system and for patients and their families. Through Medicare, the Federal Government bears about 80 percent of the costs of treatment for ESRD. In 1984, ESRD beneficiaries represented less than one-third of a percent of all Medicare beneficiaries, and accounted for almost 3.2 percent of total Medicare expenditures (Parts A and B) (47)40). The costs of ESRD treatments not borne by Medicare are paid by private insurance, Medicaid, Federal programs such as those of the Veterans Administration, and/or personal resources.

The rapidly escalating expenditures of Medicare's ESRD program have been well documented

(see table 7-4). In 1974, Medicare's ESRD program expenditures were \$229 million for 16,000 beneficiaries. By 1984, there were 92)770 beneficiaries and annual program expenditures had reached almost \$2 billion (40).<sup>7</sup> This escalation in aggregate Medicare expenditures for ESRD was not anticipated when Congress established the ESRD program in 1972. According to some observers, the cost figures Congress was given in 1972 were unreasonably low and quite misleading (25,29).

Because of the extraordinary costs of the ESRD program, Congress has sought to limit the expenditures through two laws: 1) the ESRD Program Amendment of 1978 (Public Law 95-292), and 2) the omnibus Budget Reconciliation Act of 1981 (Public Law 97-35). These laws contained, among other things, provisions designed to encourage home dialysis, which is less expensive than center dialysis, to encourage kidney transplantation, which, when successful, is less expensive over the succeeding years, and to establish composite reimbursement rates for ESRD services.<sup>8</sup>

<sup>7</sup>HCFA data on reimbursements in the End-Stage Renal Disease Program include all Medicare reimbursements that pay for services used by this population, not only the cost of dialysis and transplantation.

<sup>8</sup>Provisions to encourage home dialysis in the ESRD Program Amendments of 1978 included a waiver of the usual 3-month waiting period for entitlement for patients in self dialysis training programs, full coverage for home dialysis supplies, 100-percent reimbursement for home dialysis equipment, and authorization to establish target-rate reimbursements to encourage home dialysis. Provisions in the 1978 law to encourage transplantation included

(continued on next page)

**Table 7-3.—End-Stage Renal Disease (ESRD) Dialysis Population by Type and Place of Dialysis, 1980=85<sup>o</sup>**

Dialysis type/place	1980	1981	1982	1983	1984	1985	Average annual percent change	Percent change 1984-85
Total . . . . .	52,364	58,924	65,765	71,987	78,483	84,797	10.1	8.0
In-unit hemodialysis ..	43,271	48,011	52,559	57,029	62,462	67,559	9.3	8.2
In-unit peritoneal . . . . .	911	944	885	745	603	588	-8.4	-3.0
Home hemodialysis . . .	4,715	4,481	4,394	4,323	4,125	3,983	-3.3	-3.4
Home peritoneal . . . . .	612	646	816	790	259	231	-17.7	-13.1
CAPD <sup>c</sup> . . . . .	2,334	4,347	6,523	8,532	9,995	11,236	37.0	14.7
CCPD <sup>d</sup> . . . . .	—	—	—	—	859	953	10.9	14.4
Self training . . . . .	521	495	588	568	481	569	1.8	-48.6

<sup>a</sup>Counts are as of Dec. 31 of each year from ESRD Facility Surveys.

<sup>b</sup>This figure decreased significantly in 1984, partially due to CCPD patients being counted in this category in previous years.

<sup>c</sup>A CCPD category was added to the ESRD Facility Survey in 1984.

<sup>d</sup>CAPD, Continuous ambulatory peritoneal dialysis.

<sup>e</sup>CCPD, Continuous cycling peritoneal dialysis. CCPD rate of growth is calculated from 1984.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, Bureau of Data Management and Strategy, Research Report: End-Stage Renal Disease, 1985 (Washington, DC: U.S. Government Printing Office, in press, 1987).

**Table 7-4.—Medicare Reimbursements by Enrollees and Per Capita Reimbursements for Persons With End-Stage Renal Disease, 1974-84**

Year	Reimbursements		Enrollment		Reimbursement per enrollee	
	Amount in millions	Percent change	Number in thousands	Percent change	Amount	Percent change
1974	\$ 228.5	—	16.0	—	\$14,300	—
1975	361.1	58.0	22.7	41.9	15,900	11.2
1976	512.2	41.8	28.9	27.3	17,720	11.4
1977	641.3	25.2	34.8	20.4	18,420	3.9
1978	800.0	24.7	43.5	25.0	18,390	-0.2
1979	1,010.7	26.3	54.4	25.1	18,579	1.0
1980	1,252.2	23.8	61.9	13.8	20,229	8.9
1981	1,476.2	17.9	70.4	13.7	20,969	3.7
1982	1,660.9	12.5	77.9	10.7	21,321	1.7
1983	1,893.6	14.0	86.5	11.0	21,891	2.7
1984	1,953.5	3.2	92.8	7.3	21,051	-3.8

NOTE: Data are incomplete for most recent years due to continual updating of the payment files.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, Bureau of Data Management and Strategy, *Research Report: End-Stage Renal Disease*, 1985 (Washington, DC: U.S. Government Printing Office, in press, 1987).

Even though Medicare's aggregate and per capita expenditures for ESRD have risen annually, when adjusted for inflation in medical care, the per capita expenditure rates have remained almost constant. As shown in table 7-4, average Medicare ESRD expenditures per capita rose from \$14,300 in 1974 to \$21,051 by 1984; when corrected for inflation, however, figures for the two years were virtually equivalent (29). Data from 1974 to 1979 show that while per patient costs for the ESRD program rose 30.8 percent, during the same period, national per capita health expenditures rose by 74.9 percent and the cost per day in community hospitals rose 91.4 percent (24). The average annual rate of growth in per enrollee reimbursement levels was less than 4 percent from 1974 to 1984 (40).

Treatment for patients on chronic renal dialysis includes the dialysis treatments themselves,

(continued from previous page)

extension of the post-transplant Medicare entitlement from 1 to 3 years, clarification of coverage for living-related donor costs, and of the reimbursement principles for cadaveric organ procurement.

The Omnibus Budget Reconciliation Act of 1981 directed the Health Care Financing Administration to develop reimbursement rates for dialysis treatment based on a composite of facility and home dialysis costs in order to provide an incentive for home dialysis. The new rates implemented in 1983 were \$131 per dialysis treatment in hospital-based facilities, and \$127 per dialysis treatment for free-standing facilities. These rates replaced the \$128 previously applicable to both types of facilities. The act also had a further provision which made Medicare payment secondary to other insurance coverage for the first year following onset of chronic renal failure.

physician services both for the supervision of dialysis and the treatment of other medical problems, any required hospitalizations, and ancillary services such as laboratory tests and medications (34). Reasonable estimates of the average annual costs of treatment of a patient on chronic dialysis range from \$20,000 to \$30,000 (1982 dollars) (34). Dialysis treatments themselves account for about 70 percent of this total.

The growth in aggregate Medicare expenditures for ESRD from 1974 to 1983 is primarily attributable to growth in the number of ESRD beneficiaries. From 1974 to 1981, about 76 percent of the growth in ESRD reimbursements was due to an increase in the number of beneficiaries (8).

Hemodialysis in hospital dialysis centers is the most expensive form of dialysis treatment (34). Differences in the cost of treatment by hemodialysis performed in independent centers, by hemodialysis performed at home, and by CAPD are sufficiently small that they can be accounted for by variations in methods used in available cost estimates and by case-mix differences (34).

Medicare approval of CAPD and the use of cyclosporin as an immunosuppressive agent for transplant patients may have a significant impact on the total costs of Medicare's ESRD program in the years ahead. Also, Medicare's Part A prospective payment system may shift some costs by encouraging transplantation and outpatient dialysis.

## OUTCOMES OF DIALYSIS

Both the clinical and psychosocial outcomes of ESRD treatment are influenced by the cause of the kidney failure, comorbidity, type of treatment, and the willingness and ability of the patient to cooperate with the rigorous treatment regimen that dialysis entails. Specific information about the outcomes of dialysis in the elderly population is limited.

### Clinical Outcomes

#### Survival

Survival rates among chronic dialysis patients appear to be related to a number of factors: age at the time of starting treatment, cause of renal disease, and presence of preexisting disease at the time of starting dialysis (1).

In general, survival rates are lower among elderly patients receiving chronic dialysis than among younger patients (2)33,49). In 1984, the 1-year survival rate for patients of all ages in Medicare's ESRD program was 84.8 percent. For U.S. dialysis patients between the ages of 65 and 74, the 1-year survival rate was 77.4 percent; for patients age 75 and over, it was 68.9 percent (table 7-5). For ESRD patients over age 65 treated with

dialysis or transplant at the Northwest Kidney Center in Seattle, 5-year survival is 25 percent (1).'

The probability of survival while on ESRD treatment is closely associated with the primary cause of kidney failure. Patients with kidney failure caused by diabetic nephropathy<sup>10</sup> primary hypertensive disease have worse survival than patients with other disorders (1). For dialysis patients in Medicare's ESRD program whose primary cause for kidney failure was diabetes mellitus, the 1-year survival rate was 74.6 percent in 1984; when hypertension was the primary cause of renal failure, the survival rate was 82.7 percent (see table 7-5).

<sup>10</sup>The fact that survival rates for elderly dialysis patients are lower than those achieved in younger dialysis patients should not be used to argue against offering dialysis to elderly people. Older people in general are expected to die sooner than younger people. Infact, mortality data show that while older people on dialysis for ESRD have double the average projected 5-year mortality rate for their age group (70 percent compared with 32 percent), young people on dialysis for ESRD have 100 times the average projected 5-year mortality rate for their age group (25 percent compared with .25 percent) (15,21).

<sup>11</sup>(Diabetic nephropathy is one of the most serious complications of diabetes mellitus, a multisystem disease that adversely affects the cardiovascular system with consequent complications of the heart and the blood vessels of the brain, the eyes, and the kidneys.

Table 7-5.— Medicare ESRD Dialysis Patient Survival by Age and Cause of Renal Failure, 1980-84<sup>a</sup>

Characteristic	1980		1981		1982		1983		1984	
	Survival rate (percent)	Number								
Total	86.0	33,206	85.5	38,345	85.7	43,324	85.1	47,708	84.8	51,788
Age adjusted total	86.0		85.9		86.5		86.3		86.3	
Age:										
0 to 14 years	96.3	286	96.8	334	97.7	379	98.9	394	96.6	419
15 to 24 years	96.0	1,729	96.9	1,878	97.7	1,941	97.1	1,975	97.4	1,828
25 to 34 years	95.0	3,776	94.4	4,240	94.7	4,665	95.1	4,878	94.9	4,919
35 to 44 years	91.3	4,823	91.3	5,330	92.2	5,865	92.7	6,343	91.7	6,820
45 to 54 years	89.1	6,863	89.0	7,590	90.0	8,346	88.8	8,910	89.1	9,255
55 to 64 years	83.7	8,582	83.4	10,020	83.6	11,496	83.2	12,807	83.6	14,037
65 to 74 years	77.0	5,769	76.6	7,040	77.0	8,169	76.8	9,383	77.4	10,795
75+ years	67.0	1,378	68.1	1,913	68.1	2,463	69.6	3,018	68.9	3,715
Cause of renal failure:										
Diabetes	76.4	1,800	73.9	2,248	76.6	2,880	73.4	4,149	74.6	5,616
Glomerulonephritis	90.5	5,228	89.8	5,893	89.9	6,458	89.2	7,646	87.6	9,379
Hypertension	85.2	3,765	84.2	4,541	84.0	5,388	83.4	6,972	82.7	9,074
Other/unknown	85.8	22,413	85.7	25,663	86.0	28,598	86.2	28,941	86.6	27,719

<sup>a</sup>Includes only persons who have survived for at least one year prior to January 1 of reference year.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration Bureau of Data Management and Strategy, *Research Report End-Stage Renal Disease, 1985* (Washington DC: U.S. Government Printing Office, in press 1987).

In 1985, the most common primary renal diagnosis for elderly dialysis patients who died was hypertension with heart and renal disease (in 35.7 percent of patients who died at ages 65 to 74 and in 35.7 percent who died at age 75 and over) (46). Diabetes mellitus with other complications was the second most common kidney diagnosis of ESRD patients dying between ages 65 to 74. Glomerulonephritis was the second most frequent diagnosis for those dying at age 75 and over.

The presence of preexisting disease is another factor that affects survival. Severe hypertension, cerebrovascular disease, cancer, and coronary artery disease have an adverse effect on survival rates (1).

In 1985, the leading cause of death among Medicare ESRD patients age 65 to 74 and age 75 and over was listed as "cardiac," accounting for 25 and 27 percent of deaths in the two age groups respectively (46). Myocardial infarction was the next most common cause of death for patients age 65 to 74, accounting for almost 15 percent of deaths. In the 75 and over age group, withdrawal from dialysis was the second most common cause of death, followed closely by myocardial infarction, with each accounting for about 12 percent of the deaths in that age group (46).

### Complications and Morbidity

Patients receiving dialysis for chronic renal failure can experience problems ranging from life-threatening cardiovascular and cerebrovascular diseases to debilitating diseases of the bones or central nervous system, discomforts associated with local infections, and the need to replace catheters. These conditions can be caused by infections, metabolic changes, or mechanical problems with the dialysis equipment. Since elderly patients are more likely than younger patients to suffer from multiple health problems, they face an increased risk of developing complications.

Some problems are associated with particular forms of dialysis or dialysis settings. Problems associated with peritoneal dialysis, for example, include mechanical problems such as perforation of the bowel (1). Peritoneal dialysis is also associated with a high risk of peritonitis (i.e., inflammation of the peritoneum). The latest U.S. data on

CAPD show an infection rate of slightly more than one episode per year of treatment (35). If detected and treated early, peritonitis often can be treated at home and rarely causes death. If peritonitis recurs, however, it can eventually force the patient to change to hemodialysis.

Problems associated with hemodialysis include complications related to the vascular access site. These include prolapse or obstruction of the catheter or shunt and thrombosis of the arteriovenous fistula. Replacement or transfer of the fistula to another site may be required, and eventual depletion of convenient anatomical sites may necessitate changing to another mode of treatment. Access problems are especially likely in older patients with arteriosclerotic vessels and in diabetics (34). In dialysis centers, outbreaks of viral hepatitis are a serious threat to both patients and staff. Use of the recently developed hepatitis-B vaccine is beginning to affect the rate of hepatitis B infection, but other forms of hepatitis still occur (1). The development of cardiovascular morbidity including myocardial infarctions, cerebrovascular accidents, and advanced peripheral vascular disease may result from preexisting disease, but the pace of these disorders may be accelerated by hemodialysis (34).

Chronic renal failure is almost always associated with anemia, and this is a major factor in a lack of well-being felt by many dialysis patients (1). In most patients, anemia is due to reduced production of erythropoietin by the kidney causing a reduction in red blood cell production (10). Erythropoietin can now be made with recombinant DNA techniques, and clinical trials with synthetic erythropoietin have reduced patients' anemia. (See app. C, "Future Developments in Life-Sustaining Technologies.") Patients who have normal iron stores when they begin dialysis typically develop iron deficiency within 6 months to 2 years (1). Once this occurs, it may be treated by oral iron supplements or other methods.

Other conditions associated with dialysis include bone diseases, which occur because of derangement in the metabolism of calcium and phosphorus, and peripheral and central nervous system problems. A syndrome known as dialysis encephalopathy which includes personality changes and

an abnormal electroencephalogram and progresses to death within a few months, has been linked to the accumulation of aluminum in the blood and tissues (1).

The major problem affecting long-term survival among dialysis patients is cardiovascular disease (1). Plasma lipid abnormalities and hypertension can contribute to cardiovascular diseases. Parathyroid gland disorders and sexual dysfunction also can occur.

Various measures can be taken to prevent and reduce the complications and morbidity associated with dialysis. Among these measures are controlling hypertension, screening and vaccinating for hepatitis, rigorously controlling diet and fluid intake, and meticulously caring for the shunt or catheter site.

Elderly patients as a group tend to have more chronic diseases than younger patients, and these can affect the outcome of dialysis. Diabetes mellitus, for example, is not only a cause of kidney disease, but may be accompanied by many complications other than those related to the kidney. Degenerative joint disease poses difficulties in mobility, which can interfere with a patient's commuting to the dialysis center or his ability to manage self dialysis. Varying degrees of cognitive impairment, from mild changes related to cerebral arteriosclerosis to major problems caused by Alzheimer's disease, can interfere with a patient's ability to cooperate with the necessary therapeutic regimen including diet, control of fluid intake, as well as the dialysis. When lethal diseases such as metastatic cancer are present in tandem with ESRD, they raise difficult ethical questions about the value of continued dialysis.

### ***Psychosocial Outcomes***

Maintenance dialysis introduces major difficulties into the lives of patients with ESRD. The commitment to time-consuming, regular treatments demands that patients order their lives around a rigid schedule. Dietary and fluid restrictions must be carefully followed and travel must be carefully planned. In addition to the more serious complications associated with dialysis, wide swings in blood pressure, weakness, and nausea are common discomforts.

ESRD patients on dialysis must adjust to the idea of continued treatment for the remainder of their lives and the ever-present risk of complications related both to their renal failure and to dialysis itself. For those patients who are dialyzed in any type of center, there is the additional problem of commuting to and from the center. Transportation may pose a great burden for some elderly persons.

Some of the chronic stresses associated with ESRD include dependency on medical machinery and personnel, the constant threat of death and of reduced life expectancy, and decreased physical strength and stamina. Some researchers have reported feelings of helplessness and depression among some dialysis and transplant patients (7). A variety of losses frequently accompany ESRD treatment and can add to the emotional strain. These include the loss of participation in valued activities such as work, family and household responsibilities, and leisure activities. These intrusions threaten the individual's security and enjoyment of life and may contribute to a sense of loss of control and reduced self-esteem.

Adjusting to a technology dependent lifestyle can be very difficult. Information about the psychosocial effects of dialysis, especially for elderly patients, is limited, but some evidence suggests that elderly patients tolerate dialysis as well as, or better than, many younger dialysis patients (16,49).

A national survey completed in 1985 collected data on, among other things, how dialysis and kidney transplant patients perceived the quality of their lives (12). The data represented a balance of geographic locations, type of facility, ownership, size, academic affiliation, availability of a home training program, number of patients by type (home, in-center, CAPD/CCPD, transplant), and service area. Although the data are not representative of the entire population of dialysis and transplant patients in the United States, the information provides insights not available from other sources.

Special analyses done for OTA provide some age-group comparisons (11). Of the 859 patients responding to the survey, about 13 percent were

age 65 or older. More than half of these elderly patients were between the ages of 65 and 69; half as many were patients age 70 to 74; and the rest were age 75 or older. Elderly patients (age 65 and over) represented approximately 21 percent of in-center hemodialysis patients, 10 percent of home hemodialysis patients, and 15 percent of CAPD patients. None of these elderly patients had received a transplant.

In comparison with younger patients, ESRD patients age 65 or over had a higher well-being index, more positive feelings, less negative feelings, and a feeling that their life was easier (11). They had greater satisfaction with life in general and, in particular, with their marriages, family life, savings and investments, and standard of living. On the other hand, elderly respondents assessed their own health as poorer than that of others their age. They reported greater functional impairment, markedly less ability to work, and a much lower current employment rate than younger patients. Respondents under and over age 65 revealed generally small differences in the "total sickness impact profile." Elderly respondents reported a reasonable degree of ability to perform normal activities. A detailed analysis of overall functional status, using the Karnofsky Index (18), showed that almost half (47 percent) of the elderly patients fell in the top three categories: "normal" (2.7 percent), "normal activity" (24.3 percent), and "normal activity with effort" (23.4 percent).

Two smaller studies also provide some information on patients' satisfaction with their lives on dialysis (26)(31). One study focused on ESRD patients as a whole and the other compared patients between the ages of 55 and 65 with patients who were 65 or older. In both studies, the vast

majority of respondents said their lives were worth living, dialysis was worthwhile, and the future would be better than the present or the past. Ten percent of respondents age 55 to 65 and 20 percent of those over age 65 reported that they had considered withdrawing from dialysis treatment. Also, respondents' self-assessments of their overall health, the number of hospital admissions, and effectiveness of treatment (as measured by blood chemistries) were very similar for these two age groups.

Another measure of the psychosocial impacts of dialysis is the extent to which patients decide to discontinue treatment. National data indicate that in 1985, 8.5 percent of patients age 65 to 74 and 12 percent of patients over age 75 died as a result of "withdrawal from dialysis" (46). Withdrawal from treatment was the third most common cause of death among elderly dialysis patients.

A retrospective study of 1,766 patients in the dialysis program of the Regional Kidney Disease Center in Minnesota found that in 155 cases, dialysis was stopped before a biologic cause of death supervened (27). In one study that asked questions about the quality of life, 10 percent of respondents age 55 to 65 and 20 percent of those over age 65 reported that they had considered withdrawing from dialysis treatment (31). While suicide among dialysis patients is thought to be high, statistics on actual or contemplated "(withdrawing)" cannot be equated with suicide. Some of these cases involve patients whose will to live may be great, but for whom further treatment would be futile. Others are no longer mentally capable and the decision to withdraw dialysis is made by a surrogate.

## **MAKING DECISIONS ABOUT DIALYSIS**

Decisions about starting and stopping dialysis exemplify many of the dilemmas that attend decisions about the use of life-sustaining technologies for elderly people. Among the criteria considered in these decisions are those that pertain to the patient and those that relate to the availability of resources. These two types of criteria are sometimes interdependent. When resources

are scarce, it may be that only those patients for whom significant medical benefit is most certain will receive treatment. In times of greater abundance, the pool of treatment recipients may expand to include patients for whom the chance of significant improvement is smaller. Sometimes in fact, the pool may expand to include patients for whom treatment offers no real hope of benefit.

For over a decade after it was technically possible to provide chronic dialysis and/or kidney transplantation for ESRD patients, the scarcity of resources and high cost of the treatment placed it out of reach for most Americans. Patient selection committees were burdened with weighty decisions about who should live. The criteria they used to select patients for treatment included, in addition to medical and psychological criteria, the criterion of social worth. Discussions might focus on factors such as the social value of the patient to the community, the family responsibilities of the patient, and the patient's employability. In 1972, however, Congress acted to include payment for ESRD treatment under Medicare, and these agonizing deliberations over patient selection were ended,

Policymakers in the United Kingdom have taken a dramatically different approach to the allocation of ESRD treatment resources (see box 7-A). In the United Kingdom, "the fear of treating too many inspires greater passion than the fear of treating too few" (14).

In both the United States and the United Kingdom, how ESRD patients are chosen for treatment and which treatments they receive are determined at least as much by social priorities as by medical appropriateness. The difference in the two countries, representing two extremes of the range of patient enrollment, are accounted for at least partly by their difference in ability and willingness to make or avoid "tragic choices." As long as funding is available for ESRD treatment through

### Box 7-A—Treatment for ESRD in the United Kingdom

The United Kingdom and the United States have responded to the problem of treating ESRD patients with opposite approaches. The United Kingdom has one of the lowest treatment rates in the western world. Its enrollment rate for ESRD is only 29.7 patients per million population per year, a sharp contrast to the 38 to 47 per million population per year enrolled annually in other European countries. Between 3,000 and 5,000 people die of untreated renal failure each year in Great Britain (14). In addition to the differences in numbers of patients treated, there are differences in the choice of treatment modality. In the United Kingdom, the vast majority of treated patients receive transplants or home dialysis. In other European nations, this group is only 20 to 33 percent of the total.

The United Kingdom's policy was developed in the early 1960s by physicians' committees that were constituted by the National Health Service, Britain's national health care system. It was based on three fundamental assumptions. The first assumption is that budget allocations are never to be exceeded. The United States' policy, on the other hand, is that when the funds for Medicare are exhausted, they will be supplemented. While U.S. officials "know only with hindsight what they have spent . . . U.K. officials have a clear idea before the fact" (14). This strict adherence enforces the rationing of resources.

The second assumption in the United Kingdom is that value must be obtained for money spent. This concept is applied equally to all types of public spending; the National Health Service is no exception. The value obtained must be returned to the body whose money is spent, i.e., society. On this basis, treatment selection criteria include employability and age. This rationing seems "not only sensible but necessary—in a patently obvious way" (14).

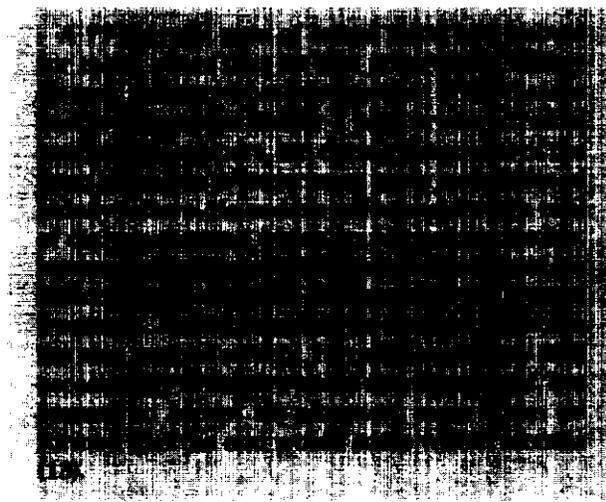
The third and final assumption is that patients in the United Kingdom are not entitled to treatment. The fact that a reliable life-saving treatment exists does not imply that a person who will die without it has a right to receive it. British policymakers use the American experience to justify this position.

. . . that ESRD patients ought legally to be entitled to treatment, however, is regarded by U.K. policy makers with a mixture of contempt and horror. Indeed, it is the American experience which is looked to as a cautionary example. In interview after interview, both administrators and physicians decried it as medically absurd—with tales of senile patients with metastatic cancer being dialyzed—and financially "out of control," attributing it to naively idealistic Congressmen and greedy proprietary dialysis center owners. America, it was always pointed out, was wealthy enough to afford such foolish extravagance; the U.K. was not (14).

Medicare's ESRD program, at least some tragic choices can be avoided.

### ***Decisions About Initiating Dialysis***

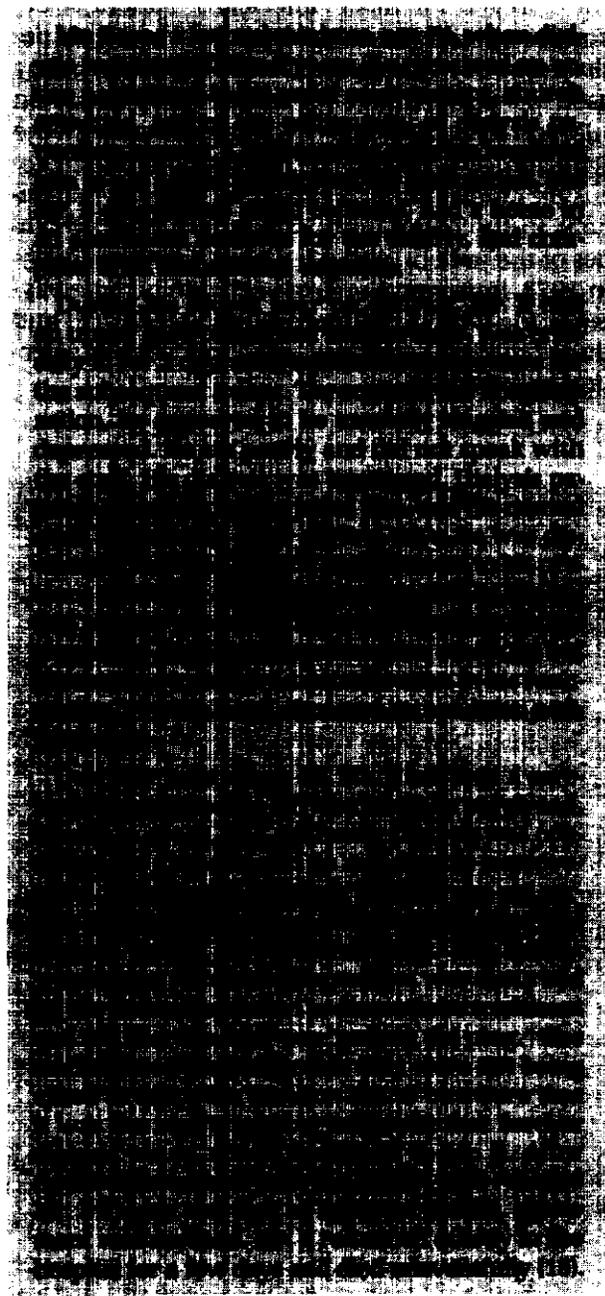
With payment for ESRD treatment widely available through Medicare's ESRD program, decisions about initiating dialysis in the United States can focus on considerations pertaining to the individual patient. One potential consideration is whether dialysis will provide medical benefit to the patient. Determining the likelihood of medical benefit from dialysis involves assessing a patient's medical status and prognosis. This involves the assessment of systems involved in the patient's renal disease, as well as any concomitant medical problems. Another potential consideration in decisions about initiating dialysis is the patient's ability and willingness to cope with strict treatment regimens. In some cases, the presence of a condition such as cancer may lead to a decision not to initiate dialysis. The following case describes an elderly man who was unwilling to undertake chronic dialysis treatment:



### ***Decisions About Stopping Dialysis***

In some cases, a point may be reached where dialysis appears to be of no further medical benefit, where a patient does not wish to continue, or when a surrogate decision is needed. This point may come in a matter of weeks or after many years of dialysis treatment.

Decisions to discontinue dialysis are often more difficult than decisions to start dialysis. The following case illustrates some of the decisionmaking dilemmas that can arise:



Strong Memorial hospital, the tertiary care center for the Rochester, New York area, deals with decisionmaking dilemmas for some dialysis patients by offering patients a trial treatment period

at the end of which the decision to withdraw dialysis may be considered (13). A trial treatment period allows a patient (and family) an opportunity to "try out" dialysis without making an irreversible decision. It also gives physicians time to establish a more precise diagnosis, adjust therapy to an optimal level, and better assess prognosis.

A 69-year-old widowed woman with a history of high blood pressure, adult-onset diabetes, and several heart attacks had begun maintenance dialysis 6 months before being transferred to Strong Memorial Hospital. In the hospital, she was restricted to bed because of her heart disease, which caused chest pain with minimal exertion and shortness of breath. After diagnostic studies, her dialysis treatments were altered to minimize the fluid overload affecting her heart, and her medications were adjusted to improve her heart function. During the first week in the hospital, the medical team of cardiologist, nephrologist, dialysis nurses, social workers, and others discussed her medical, personal, and social situation with the patient and her daughter and son-in-law.

When it was evident to everyone that the likelihood of improvement was nil, the concept of a trial of maximum therapy for a finite period was raised first with her daughter and son-in-law, and then with the patient. These interactions were delicate and sensitive. The patient accepted the concept of a trial of intensive therapy with the understanding that a complete reevaluation of her status would be made after 4 weeks of intensive therapy.

At the end of a month, she was unable to move out of bed without experiencing severe chest pain and shortness of breath. The decision to discontinue dialysis was considered again. Her son-in-law was supportive of his wife's wishes. Her daughter and privately, the two volunteered to care for the patient would be accepted with long-term care in their home. The patient was informed that there was little hope for improvement in her condition. Later in the conversation and agreement to stop dialysis, the patient and physicians were joined by her daughter and her husband in order to assure the patient that they understood her problem and wanted her to come home with them. The woman decided that she would be more comfortable in her daughter's home for her last few weeks. The emotions of this discussion were intense and everyone had

tears on their cheeks. The patient died 19 days after discharge from the hospital, in her daughter's home (13).

Although older patients in general report a high degree of life satisfaction while undergoing chronic dialysis (49), they do withdraw from dialysis at higher rates. In one study, withdrawal was the cause of death in 40 percent of elderly people compared with only 22 percent for all ages (16). The high rate of discontinuance may occur because factors that can trigger the decision, such as multiple underlying diseases, are more common and occur earlier in dialysis in older patients (16).

The study of 1,766 ESRD patients at the Regional Kidney Disease Center in Minnesota between 1966 and 1983 (27) cited previously found that dialysis was discontinued in 155 patients of all ages. These 155 patients represented 9 percent of the 1,766 patients who received treatment and 22 percent of all deaths. The investigators concluded that "stopping treatment is a common mode of death in patients receiving dialysis, particularly in those who are old and those who have complicating degenerative diseases" (27). Dialysis was discontinued in 1 of every 11 patients and in 1 of every 6 over age 60.

Notes describing the competence of patients from whom dialysis was withdrawn were found in 132 charts. Half (62) of these patients were said to be "competent," and of these, 58 made the decision to withdraw on their own. In the 64 patients deemed "incompetent because of dementia, strokes, or coma" the decision to withdraw dialysis was made by a surrogate. In all the "incompetent" patients and a majority (61 percent) of the "competent" patients, a new medical complication preceded the decision to withdraw dialysis. Brain disease was the most common complication leading to withdrawal of dialysis. Of the 155 patients, 44 had dementia. The majority of all patients who discontinued dialysis were on in-center dialysis (73 percent). The mean treatment period among patients from whom dialysis was withdrawn was 30 months; only 10 percent of patients had been on dialysis as long as 3 years. Mean survival after dialysis stopped was 8.1 days. Of the 155 patients who stopped dialysis, 45 had

diabetes. In all age groups except the oldest, dialysis was stopped three to five times more often among diabetic patients. Among nondiabetic patients, degenerative diseases such as heart and vascular disease, cancer, and chronic pulmonary disease were significantly more common in patients from whom dialysis was withdrawn than in patients who remained on dialysis.

The site of residence could be ascertained for 98 of the 155 patients. At the time a decision to discontinue dialysis therapy was made, 81 percent of these patients lived at home. At the time of death, however, most of the patients who discontinued dialysis were in hospitals. A small percentage died at home (13 percent) or in hospices (4 percent).

### ***Decisionmaking Procedures***

Initially, ESRD therapy is considered by a patient's physician, either a family physician who refers the patient to a nephrologist or a nephrologist who has followed the patient with renal disease for a long time and recognizes that the disease has reached the stage where dialysis and/or renal transplantation should be considered. In some centers, especially the larger ones, a review committee meets regularly to consider the treatment to be recommended for each new ESRD patient—the different types of dialysis, a kidney transplant, as well as a recommendation not to treat at all. Such committees usually include representatives from among the following fields: nephrology, transplantation, urology, nursing, social work, clergy, law, hospital administration, nutrition, and the dialysis center staff. Often, the patient and/or patient's family are asked to attend so they can understand and participate in the decisionmaking process and ask questions of the health team.

There is almost nothing in print about the criteria dialysis centers use to select patients for dialysis. In January 1984, the Section on Renal Disease, Department of Internal Medicine, University of Arizona Health Sciences Center, prepared a written policy in preparation for a site visit by the Joint Commission on Accreditation of Hospitals. This policy, outlined below, is representative of the approach described to OTA by many nephrol-

ogists responsible for dialysis patients. Chronic dialysis therapy is provided to every patient, regardless of age, who:

1. grants fully informed consent;
2. has chronic, irreversible ESRD;
3. has a reasonable expectation of a quality of life acceptable to himself or herself; and
4. desires and can cooperate with such therapy (48).

One study of the criteria used by physicians to select patients for ESRD treatment at 373 dialysis centers and 80 transplantation hospitals (20) rated potential patient selection criteria along a 5-point scale to indicate their importance in decisionmaking. Virtually all respondents considered the following criteria important: prognosis, psychological stability, and likelihood of medical benefit. A very large majority (nearly 90 percent) of respondents said they would consider the patient's willingness to participate in treatment and/or consider the patient's age in decisions about treatment. Only 10 percent of responding dialysis facilities said they currently excluded patients because of advanced age, but 85 percent of dialysis centers reported that "under conditions of significant scarcity," they would do so.

There is no uniform mechanism for making decisions to withdraw dialysis. Although most physicians consider it their responsibility to make recommendations about appropriate medical care for patients, the ultimate decision about discontinuing treatment usually rests with the patient or patient's family (27). The case of 78-year-old Earle Spring highlights the legal, ethical, and medical issues that can surround decisions about the termination of dialysis for patients who are no longer decisionally capable (see box 7-B).

### ***Ethical Issues***

According to some people, because the ESRD program covers treatment costs for virtually all ESRD patients regardless of age, diagnosis, or any other factor, there is a strong financial incentive to provide treatment for all patients who reach ESRD, and to continue that treatment as long as it is able to sustain life (25). In some cases, however, the initiation or continuation of dialysis (or

other life-prolonging treatment) may be a burden to the patient.

Any analysis of ethical issues surrounding decisions about initiating and terminating dialysis treatment must recognize that Western culture and the United States place great weight on the

importance of the individual and the right of self-determination or autonomy. When possible, the patient must be allowed to decide if a commitment to long-term dialysis is worth the trade-off. As discussed throughout this report, medical staff and patients often will differ significantly in what they perceive about quality of life. Some patients with ESRD are incapable of making their own de-

### Box 7-B.-The Earle Spring Case

In October 1977, Earle Spring, 78, was diagnosed as having chronic organic brain syndrome by a psychiatrist. In November of the same year, he suffered a minor scratch on the instep of his foot. This rugged outdoorsman eschewed physicians and hospitals and left his scratch untreated until his foot had become gangrenous. He was hospitalized, then developed pneumonia and kidney failure. Dialysis was initiated, and Spring improved but required three 5-hour dialysis sessions per week. His mental deterioration became more pronounced. After more than a year of treatment, the nephrologist informed Spring's son Robert that his father was not benefiting from dialysis. He suggested that initiating dialysis for a man Spring's age might have been a mistake and that it would be best if the treatment were ended. The son and the wife agreed with the physician and requested that the treatments be stopped.

Because of the Massachusetts Supreme Judicial Court's 1977 *Saikewicz* ruling (36), decisions of such significance have to be made by the courts rather than by families and physicians. Robert Spring, who had been appointed temporary guardian, petitioned the Franklin County Probate Court for an order to terminate the dialysis treatments. An attorney *ad litem* to represent the best interests of the patient, Mark I. Berson, insisted that the court could not render a "substituted judgment" without some evidence from Spring's lucid moments on the subject. On May 15, 1979, Judge Keedy entered a judgment permitting Robert Spring "to refrain from authorizing further life-prolonging treatment" for his father. Berson was not satisfied and appealed. Judge Keedy then entered a new order stating that Spring's wife and son, together with the attending physician were to make the decision. Berson appealed again. The Court of Appeals upheld the probate court's action and rejected Berson's position on the need for an express statement of intent to withhold treatment. On January 10, the Supreme Judicial Court heard the case and concluded that the trial judge's finding, that if Earle Spring were competent he would not choose to receive life-prolonging treatment, was correct. Spring's guardian was directed to refrain from authorizing any further life-prolonging treatment for his father.

The staff at the Holyoke Geriatric Center was appalled over the decision to stop dialysis treatment. Two nurses on the 3-11 shift asked Spring if he wanted to die and he reportedly replied, "No." A psychiatrist had previously evaluated Spring as incompetent, but the nurses, taking his statement as proof of Spring's desires, brought the story to the local newspaper which used it as headline news. Berson replied immediately. On the basis of an affidavit by a right-to-life group, he petitioned Judge Keedy to reinstate dialysis treatments until new evidence of Spring's competence could be gathered. Right-to-life activists hired a lawyer to petition the probate court to admit them as parties to the case. Judge Keedy denied the petition to reinstate dialysis treatment. Berson appealed again and the appeal was granted by the Supreme Judicial Court which appointed five psychiatrists and geriatric specialists to determine Spring's mental status. During that time, Spring was admitted to the hospital and diagnosed as having infection and pneumonia. He responded to medical treatment and was returned to the nursing home in an extremely weakened condition. The day before the competency hearing was scheduled, Spring died. The next day, the five court-appointed physicians filed their report: Spring "was suffering from such profound mental impairment that he had no idea where he was or what was going on. The dementia was not related to the kidney failure, was untreatable, and irreversible." Had he not died the day before, the responsibility for deciding to stop dialysis treatments would have rested where it had 14 months previously-with the court.

SOURCE: J.J. Paris, "Death, Dying and the Courts: The Travesty and Tragedy of the Earle Spring Case," *Linacre Quarterly* 49:26-41, 1982.

isions about dialysis treatment, and the decisions have to be made by a surrogate.

### ***Legal Issues***

A 66-year-old widow had been on maintenance dialysis for 8 years. In 1978, she had a stroke that left her left side paralyzed. In 1983, she had another stroke that left her with a right-sided paralysis, unable to communicate or to perform the simplest task. Her heart was unstable and she required monitors and other resources available only in the medical ICU. All medical professionals involved in caring for the patient agreed that the patient's outlook for recovery and return to a meaningful existence was hopeless, but three of her sons were adamant that every possible treatment be provided. Without the consent of the legal next of kin, no one felt that it was ethically or legally right to discontinue treatment. The patient remained hospitalized, mostly in the ICU for

69 days. She died of overwhelming infection, dialyzed until the day before her death (13).

Few legal cases have arisen as a result of ESRD treatment or decisions. One reason for this may be that dialysis centers are particularly cautious not to deny treatment if the patient and/or family insist on receiving dialysis, even though the kidney team recommends against it. The University of Rochester kidney team has commented that if there is a potential for litigation, patients will continue to receive dialysis even if the kidney health care team believes treatment should be stopped (13). Similar statements have been made by dialysis team leaders across the country. Leroy Shear, Director of the Western Massachusetts Kidney Center noted, "The way I practice medicine is very much determined by what the courts tell me to do" (17)28).

## **FINDINGS AND IMPLICATIONS**

An increasing number of elderly patients with ESRD are being treated by dialysis. Almost half the new patients starting treatment in the United States are age 55 or older, and almost half the patients enrolled in Medicare's ESRD program are 55 or older (1). These numbers will probably continue to increase (1). Experience has shown that elderly patients tolerate dialysis reasonably well, and with resources and payment now available through Medicare's ESRD program, age is not a prominently used criterion in the selection of patients.

The American experience with dialysis for ESRD presents two major concerns: 1) the high costs of dialysis borne by the Federal Government, patients, and their families; and 2) ethical problems accompanying the decisionmaking process involved with starting and stopping dialysis treatment.

Through Medicare, the Federal Government bears about 80 percent of the cost of treatment for ESRD for about 103,000 patients (44). As noted earlier, the cost of Medicare's ESRD program is now well over \$2.1 billion annually, and aggregate expenditures have been increasing each year. In-

creases in aggregate expenditures are due largely to growth in the ESRD population. Despite the fact that Medicare's ESRD population includes a higher percentage of older and sicker patients, per capita expenditures (when adjusted for inflation) have remained fairly constant or even decreased over the life of the program (25).

In part because there are Medicare funds available to cover treatment, dialysis for ESRD is currently available to Americans of all ages. Although elderly people as a group tend to have more complications and lower survival rates than younger people, a patient's age alone is not a good predictor of the outcome of dialysis. Other important considerations include the cause of a patient's renal failure and the presence of comorbidities.

Typically, a decision to initiate dialysis involves a recommendation from the health care providers involved in a patient's care. Increasing emphasis is placed on the importance of patient autonomy, however, and major efforts are made to inform patients and their families about all aspects of their disease and treatment. In some cases, patients may decide that they do not want dialysis treatment even if it may prolong their lives.

For some patients, a point may be reached where dialysis is no longer beneficial. When a recommendation is made to discontinue dialysis therapy, agreement is sought from the patient or, if the patient is incapable of participating, from the patient's next of kin. In the absence of clear permission from either the patient or surrogate, fear of litigation sometimes keeps kidney care teams from discontinuing dialysis even when it is no longer medically beneficial.

Many elderly patients with ESRD have been restored to productive and meaningful lives through

dialysis treatment. others are able to enjoy a quality of life that they find acceptable. Some elderly patients, however, choose to discontinue dialysis.

Clearly, the ethical decisions associated with dialysis and its dilemmas must be approached individually. The solutions to the critical dilemmas associated with ESRD and dialysis, however, may have important implications for other catastrophic illnesses and life-sustaining technologies.

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