Dialysis After Nearly a Decade

When the government started paying for dialysis, the patient population changed, and difficult problems arose

On the Saturday morning of 30 September 1972 the Senate hurriedly passed an amendment to the Social Security bill, thereby extending Medicare coverage to patients with kidney failure. Thus began the End Stage Renal Disease (ESRD) program, an extraordinary experiment in health care delivery, the wisdom of which has been questioned but the continuation of which is a near certainty. The program is a study of national health insurance in a microcosm, and a number of physicians and close observers say they question the government's ability to administer even a program this comparatively small and self-contained.

This is the second of two articles on the politics, economics, and sociology of dialysis.

The program now reaches about 50,000 patients and costs the government $1 billion a year in medical bills. Many patients who would have died of kidney failure are now alive, but all are not necessarily well. The "new" dialysis population includes patients with serious chronic illness such as cancer and heart disease and senile patients who are delivered to dialysis centers three times a week from their nursing homes. For some patients, the dialysis machine has become the equivalent of the respirator, sustaining life when hope of regaining health is gone. In light of the enormous costs of the program, some of the benefits are questionable.

The impetus for the ESRD program began in the 1960's, when it first became possible to save the lives of patients whose kidneys had failed. But dialysis was new, experimental, and costly, with limited facilities that could not possibly accommodate the numbers of individuals who could benefit. Although kidney transplants were sometimes done they were often unsuccessful; about 40 percent of the patients died within a year. The more common way to save these patients was to dialyze their blood with artificial kidney machines.

In the early 1960's dialysis was highly publicized as a heroic and dramatic procedure. Blood is circulated from a vein in the patient's arm through an artificial kidney machine, where it is cleansed of toxins before returning through a tube to the patient's arm. The cost of dialysis, however, was near $40,000 a year for each patient. As was pointed out in newspaper and magazine articles at the time, someone had to choose which patients should be offered dialysis and which allowed to die. In Seattle, an anonymous committee of seven community members made these decisions. In Boston, Constantine Hampers recalls, "We [the doctors] used to sit around and decide who would go on dialysis. I felt terrible about making those decisions and tended to blot them out of my mind." Today, Hampers is chairman of the board of National Medical Care, a company that provides dialysis services at outpatient centers.

In 1972, when the amendment to provide federal funds for dialysis or kidney transplants was being debated, the senators were all too aware of the ethical problems that arise when doctors or lay committees have to decide how to allocate scarce medical resources. The only thing standing in the way of more machines was money—not technology. Vance Hartke (D-Ind.), who sponsored the amendment, asked, "How do we explain that the difference between life and death in this country is a matter of dollars?" Senator Lawton Chiles (D-Fla.) said, "in this country, with so much affluence, to think that there are people who will die this year merely because we do not have enough of these machines and do not have enough money."

The decision to start the ESRD program was founded on humanitarian motives. But like other programs in which it was "only a question of money," it has come back to haunt the government with a set of perplexing problems, not the least of which is a tremendous growth in costs.

In 1979, 48,000 dialysis patients were treated at a cost to the government of about $1 billion, up from $250 million in 1972. (A few thousand patients receive kidney transplants each year, but most of them are given kidneys from cadavers, more than half of which are rejected within 1 year. So the ESRD program is essentially a dialysis program.) Although end stage renal disease patients constitute only 0.2 percent of the total Medicare population, they account for 5 percent of the Medicare funds. Yet, when inflation is taken into account, the costs of dialysis per patient, now about $28,000 a year, have decreased since the program began. The number of patients being kept alive after kidney failure, however, has increased more than eightfold since 1972 and is expected to continue rising to about 70,000 patients by 1990. High as it is, the $1 billion figure understates the true costs to the government. As Richard Rettig of the Rand Corporation points out, a substantial number—there are no good data available on just how many—of the patients also collect federal disability payments.

When the government began paying for dialysis, the patient population changed. The average age of patients in 1972 was between 37 and 43, and fewer than 20 percent were over the age of 50. Now the average age is more than 50. According to Christopher Blagg, director of the Northwest Kidney Center in Seattle, it used to be unheard of for elderly and very sick patients to be dialyzed.

John Sadler of the University of Maryland Medical School in Baltimore was one of the physicians who lobbied for the ESRD program. Looking back, he sees that he and his colleagues were naïve. "We had [in 1972] what was in many ways an idealized population. A large fraction of the patients were in a productive period of their lives. They were young and [apart from their kidney failure] had little else wrong with them." Sadler and others agreed that most such kidney patients could be rehabilitated to lead productive lives.

All too often now, rehabilitation has proved to be impossible or has been neglected. "We have patients who have never worked, patients who are retired, and patients for whom a low paying job can't compete with the disability payments available to them," says Sadler. In the days before the ESRD program, when resources were scarce, they were spent on patients who could benefit from them medically in the most complete sense—not only by having blood detoxified but by being made well to resume

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useful lives. Now, with payment for all, the program is getting a lot of people whose lives can't be rehabilitated by dialysis alone, and that may account for the "failure" to rehabilitate.

Rettig, who has closely followed the politics and economics of the ESRD program, says that whether there is any effort to rehabilitate patients who are capable of working depends largely on the dialysis unit and the physician in charge. For example, one patient from a central Ohio dialysis center spoke at a seminar Rettig conducted and revealed that he was the only one of the approximately 40 patients at the center who was working. "Moreover," Rettig recalls, "this patient said that the other patients found it amazing to think that it was possible to return to work." A patient from a Washington, D.C. center who works full time says that his center's directors discouraged patient rehabilitation when they moved back the starting time for the evening dialysis shift from 7:00 to 5:30 p.m. When he complained that he didn't even finish work until 5:30 and the center is more than 10 miles from his office, he says he was told that he was being unreasonable.

The picture that Sadler, Rettig, and others paint of dialysis patients hardly resembles that envisioned by the Senate when it debated the amendment that established the ESRD program. In 1972 Senator Hartke said, "Sixty percent of those on dialysis can return to work but require retraining and most of the remaining 40 percent need no retraining whatsoever. These are people who can be active and productive, but only if they have the life-saving treatment they need so badly."

According to doctors who treat them, dialysis patients are often deeply unhappy. Edmund Lowrie, director of the Kidney Center in Boston, says that when patients are tested with the Minnesota Multiphasic Personality Inventory, their scores show that many are depressed and have a tendency toward hypochondria. "They feel captured by the medical profession," Lowrie says.

Alan M. Goldstein, a clinical psychologist at the John Jay College of Criminal Justice in New York, says that dialysis patients have a suicide rate seven times higher than the national average. This is comparable to the rate for patients with other chronic diseases, he explains. Some kill themselves outright, but others do so indirectly by missing medical appointments and failing to follow the strict diet required of those on dialysis.

In the early days of dialysis, suicide was essentially nonexistent, according to Belding Scribner of the University of Washington in Seattle. But in 1964, Scribner predicted that as dialysis became less of an extraordinary treatment the number of suicides would increase. "Now dialysis is perceived as a burden rather than a way of saving lives," he points out. Before the ESRD program, patients with kidney failure expected to die and were so glad to be alive when they were given dialysis that suicide was virtually inconceivable. Also, of course, the early patients were carefully selected—they were young and had positive attitudes toward life, Scribner explains.

Now that dialysis is taken for granted, its burdensome aspects are brought into sharp focus. It is impossible for dialysis patients ever to forget that their kidneys have failed, for they must adhere to a rigid diet that is low in sodium, low in potassium, and low in fluids. Some patients, for example, are allowed only a pint of fluid each day. Sandra Madison, head nurse at the Kidney Center, explains that if patients break their diet regularly, they can develop life-threatening potassium or fluid imbalances. She has seen patients gain as much as 20 pounds in the 2 or 3 days between dialysis sessions because they ignored their fluid restrictions. Dialysis then can be extremely uncomfortable, causing severe cramps, weakness, and nausea. "The body does not easily adjust to extremes," Madison says.

Dialysis itself takes a toll on patients, whether or not they break their diets. The patients are not physiologically normal; they are anemic, prone to bone degeneration, and male patients often are impotent. Then there is the inconvenience of dialysis. It takes an average of 4 hours for a dialysis treatment and patients must be dialyzed three times a week. Although some patients are dialyzed at home with the help of a trained family member or friend, most go to dialysis centers such as the proprietary ones run by National Medical Care. But the staffs at the centers sometimes have strained relationships with the patients and the patients say they have inadequate avenues of complaint.

Lowrie explains that the close long-term relationships between patients and staffs at dialysis centers often led to difficult situations. The patients develop close ties with the doctors, nurses, and technicians, but in some cases these ties are not helpful. Lowrie says, "There are rules of behavior. A professional cannot show aggression. The patient is unbridled and can be unkind, to say the

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Use of Killer Weed Grows in Third World

"We need the world," says Kirt Wayne of Tobacco Associates, a Washington-based association that represents tobacco growers. And to the chagrin of international health officials, they are getting it.

With a slump in sales to North America and Europe, the U.S. tobacco industry has found in the developing countries a vast untapped market. "Try Winston," reads one of the Third World slogans, "the great taste of America." Aggressive advertising has paid off. Between 1974 and 1979, the average value of the tobacco products and leaf sent beyond U.S. borders went from $650 million to $2.15 billion. In Africa this has had a clear impact. Per capita cigarette consumption there during the past decade has increased 33 percent. Says Wayne: "The blended cigarette, which relies on high-quality American tobacco, is growing in popularity around the world."

International health officials are worried that the prosperity of the U.S. tobacco industry is now linked to the exportation of a potentially deadly habit. "The threat to many developing countries is immediate and serious," warns a recent World Health Organization report. "In the absence of strong and resolute government action, smoking disease will appear in developing countries before communicable disease and malnutrition have been controlled, and the gap between the rich and poor countries will thus be further expanded."

In response to this problem, the U.S. Department of Agriculture this year agreed to stop shipping tobacco to poor countries under the "Food for Peace" program. Up until this decision, between $17 million and $66 million in tobacco products had been sent each year during the past decade to such countries as South Vietnam, Cambodia, and, most recently, Egypt. Despite the halt to this practice, USDA still supports the U.S. tobacco industry, and thus indirectly the export of tobacco. Through the Commodity Credit Corporation and the price-support system, USDA spent more than $337 million on the U.S. tobacco industry in 1979 alone. When this reporter called

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least. It can be hard to maintain a professional distance."

The patients, on the other hand, often tell a different story. Some say they dislike and distrust their doctors but have no choices because they have nowhere else to go for dialysis. Dialysis facilities are centralized and to switch from one center to another often requires commuting a long distance, which can be especially difficult for sick patients. Some patients claim their doctors are insensitive to their complaints and tell them bluntly that if they are unhappy, they can leave. Others say that they are afraid of their doctors since their very lives depend on the doctors' good graces. Doctors such as Lowrie, Sadler, and Blagg say these complaints are familiar and hard to deal with, especially since emotionally upset patients sometimes selectively hear or misinterpret what their doctors say.

Since the ESRD program is federally sponsored, patients feel that Congress is a recourse. Yet they say that when they complain to their senators or representatives or to federal officials, they get only polite responses that, essentially, brush off their concerns. For example, a Washington, D.C. man has an entire file of letters he wrote to various officials about what he thinks is substandard medical care in the center where he is dialyzed. In no case did he get an adequate response, he says.

A government official, who wishes not to be named, agrees that patients have a hard time being heard. "It's not that the patients have not complained to the right person. There *is* no right person to complain to."

A number of physicians believe that the government is remiss in not keeping tabs on quality of care. There is no way to pick out centers with abnormally high mortality rates, for example, since even such minimal data are not available.

Sadler, who has long been politically involved in the design of the ESRD program, says the government "has a total disregard for quality of care." The government has data in its own computers that provide at least a gross estimate of the minimum quality of care, but that information is never retrieved, according to Sadler. He says that the government, in its bills for services, has data on such things as the number of times patients are hospitalized each year, the number of times they receive blood transfusions, and the number of times they are dialyzed outside their usual setting (in a hospital, for example, if they usually are dialyzed in an outpatient center). "We have told the government for the past 8 years how to measure quality of care," Sadler says. He can only conclude that the federal bureaucracy is not set up to deal with this matter.

Blagg, another of the political doctors, agrees with Sadler. "The government talks about quality of care but it hasn't done anything yet to measure it," he says. Blagg thinks that Sadler's suggested measures are reasonable.

In addition to their concerns about patient rehabilitation, patient complaints, and the lack of even the most minimal information on quality of care, physicians and other health care specialists say they are disturbed by the increasing number of terminally ill or incompetent patients who are dialyzed. In other countries, England, in particular, doctors do not refer such patients for dialysis. But in this country, where Congress intended that dialysis be available to all those who need it, it has become legally and morally difficult to refuse patients.

Blagg and Scribner, for example, tell of a woman patient of theirs who, at age 67 and after 12 years of dialysis, began having severe convulsions. She spent more than 3 months in a hospital at a cost of more than $50,000 while in a stupor from repeated seizures and high doses of anticonvulsant medications.

Her family wanted her dialysis to be discontinued but Scribner and Blagg were strongly advised by the state attorney general not to stop the dialysis treatments. The legal argument was that only the woman herself could request that her dialysis be terminated. She, of course, could not make that request because of her mental condition. This quandary was resolved, Blagg says, when the patient died.

Then there is the highly publicized case of Earle Spring, a nursing home patient in Springfield, Massachusetts. Spring is senile, although he has lucid periods, and his family has requested that his dialysis be terminated. But the Massachusetts courts have ruled that the decision on whether to terminate Spring's dialysis must be made on the basis of what he would want if he were capable of communicating. At present, the final decision has not been made and Spring continues to be dialyzed.

Spring and the patient of Scribner and Blagg are extreme cases, although, according to Scribner and others, incompetent patients are growing in number. But there is still another class of patients for whom the value of dialysis has been questioned. These are patients who, in addition to kidney failure, have underlying severe chronic diseases.

Sadler is quite candid in describing what he says to these patients, who, he explains, include patients with disseminated cancer, patients with debilitating heart disease, and others such as blind, depressed diabetics. "I sit down and say, 'Dialysis will correct your uremia but, because you have a progressive disease, the struggle to survive will be difficult and death also will be a struggle.' " Usually, Sadler says, the patients ask him some questions, then conclude that they do not want dialysis.

It is Sadler's opinion and that of others, including Hampers, that the current federal policy of offering dialysis to everyone is unwise and a waste of resources. Hampers suggests that, difficult as it may be, the government could appoint a committee to set up guidelines for deciding whom to treat. Scribner points out, however, that the setting up of such a committee would be impossible. It would have ramifications far beyond that of dialysis and the government would not want to get into the business of deciding whose lives are worth saving and at what cost.

A number of physicians and health care specialists say they are deeply disappointed in the way the government has run the ESRD program. Both physicians and patients tend to become frustrated when faced with bureaucratic entanglements that seem to be routine. Typical of the complaints that are voiced is Blagg's statement that "There has been and still is no effective leadership for the program at the federal level." Scribner says, "The government has failed completely. No one is in charge." Says Rettig, "The data system is a shambles." And says Lowrie, "The government has been totally unable to manage the program."

Worse yet, say these specialists, there is no indication that the situation will change. Since its inception, the program has been plagued with bureaucratic reorganization, high personnel turnovers, and a lack of efficient organization.

Philip Jos, who was until very recently the director of the Office of ESRD in the Social Security Administration, responds by saying that these criticisms must be put into perspective, that so far over 100,000 individuals have benefited from the program. Moreover, according to Jos, the government has been responsive to the community's views and has not been reluctant to change its policies when necessary. "Notwithstanding the problems of the program, when one fairly views its accomplishments a judgment that it represents a complete failure of program management by the government is unsupportable," he says.

—GINA BARI KOLATA