

Life and Death in a Welfare State: End-stage Renal Disease in the United Kingdom

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We die with the dying:
See, they depart, and we go with them.
(T. S. Eliot, "Little Gidding")

THIS IS A CASE STUDY OF HOW A NATIONAL health system in an advanced Western democracy confronts an affliction which poses a life or death issue for thousands of its citizens every year. The health system is the National Health Service, the democracy is the United Kingdom, and the affliction is end-stage renal disease. This case is not unique; if it were, it could hardly serve as an illustration. Nor is it without the ambiguities that real life attaches to phenomena, like bits of fried fish sticking to a pan. But at its center is a rather unusual starkness, for the life or death question is less often whether the medically indicated therapies will succeed than whether they will even be tried.

End-stage Renal Disease

The kidneys are the body's main organs of excretion. They are, however, subject to serious, progressive, and irreversible deterioration, usually

as a result of glomerulonephritis (Bright's disease), pyelonephritis (scarring from reflux and infections), polycystic kidney disease, and vascular disease (chiefly, hypertension). This condition is called chronic renal failure, and is marked, among other consequences, by the kidneys' decreased ability to extract excess fluids and poisonous wastes from the blood. Anemia, edema, and infection frequently accompany the condition, and the functioning of the brain, intestine, heart, skin, and other organs is impaired. Eventually, chronic renal failure nearly always reaches the point where it is termed end-stage renal disease (ESRD), which, as the name suggests, is invariably fatal.

By the 1960s, two principal treatments for ESRD had been developed. One utilizes a dialysis machine, at first called an artificial kidney. A continuous flow of the patient's blood is diverted to a semipermeable membrane, which permits excess fluids and wastes to pass through its tiny holes like water through a sieve. The blood, now with tolerable fluid and waste levels, is then returned to the patient.

For patients using the kidney machine, dialysis is typically necessary three times a week for approximately three to six hours per session. Enervating side effects, in addition to profound emotional and interpersonal strain and debilitating physiological disorders, are common (Czaczkes and Kaplan De-Nour 1978, chaps. 5-6; Rosa, Fryd, and Kjellstrand 1980; Levy 1979; Farmer, Snowden, and Parsons 1979).

At first, it was believed that dialysis was so complicated and dangerous that it required a hospital setting (de Wardener 1966, 115-17), but after the feasibility of dialysis at home was demonstrated (Merrill et al. 1964; Baillod et al. 1965), many physicians and patients began to conclude that where appropriate, it was preferable. Though preparation, operation, and clean-up are time consuming and sometimes stressful, the risk of infection is less and the patient's convenience, comfort, and sense of control over his own life are greater. Home dialysis patients tend to have superior survival and rehabilitation rates.

From the outset, machine dialysis, whether performed in the patient's home or in a hospital or dialysis center, has remained by a large margin the most widely utilized therapy for ESRD in the world.

In the late 1970s, a variant, the less grueling continuous ambulatory peritoneal dialysis (CAPD), began to appear as an alternative treatment in certain cases. Here, a catheter is inserted into the patient's abdominal cavity, and wastes and excess fluid pass through the cavity's natural lining, the peritoneum, into a bag, which, when full, is simply

discarded and replaced. This procedure is repeated four times a day and, in all, consumes about two and a half hours.

The second major treatment is kidney transplantation. It began with identical twin donors (Merrill et al. 1956), and became feasible for genetically different donors with the development of drugs that successfully suppressed the body's normal rejection of foreign tissue. Even today, however, 25 per cent of United Kingdom first cadaveric kidney transplants fail during the first three months, and 40 per cent do not survive two years (Broyer et al. 1982, 16a), a success rate about half that of the United States (Krakauer et al. 1983). Despite this, its promise of far greater physical and mental vigor (Kaplan De-Nour and Shanan 1980)—as well as its freedom from the oppressive dialysis routine—has meant that from the earliest days, patient demand for transplantation has vastly exceeded the supply of available kidneys.

There is some dispute as to the incidence of treatable ESRD. In the United Kingdom, the "often quoted" rule of thumb (Laing 1978, 16) is that forty new patients per million population (PMP) are suitable for treatment (Branch et al. 1971; Pendreigh et al. 1972; McGeown 1972). Many contend that in excluding those under age 5, over age 60, or with complicating diseases, this figure is much too low, and even a former chief medical officer of the Department of Health and Social Security (DHSS) conceded that it is "now regarded as an underestimate" (Yellowlees 1982, 116). American nephrologists generally give 100 PMP as their estimate (Luke 1983, 1593), and if age and the presence of complicating disease were ignored completely, the number might soar to 150 (Laing 1978, 18; Berlyne 1982, 189). ESRD must be termed an uncommon, if not precisely a rare condition.

The United Kingdom Response

Of those ESRD patients undergoing treatment in the U.K. in 1982, 24.8 percent were on home dialysis, 16.7 percent on hospital dialysis, and 12.7 percent on CAPD; 44.7 percent had had successful transplants. Compared to other nations, the U.K. is unique in its stress upon transplantation and home dialysis, and relies upon nonhospital-based therapies over hospital-based therapies by a ratio of nearly 5:1 (Broyer et al. 1982, 7). In contrast, in France hospital-based therapies are

preferred by 2:1, in West Germany by 3:1, and in Italy by almost 4:1. While it is widely acknowledged that nonhospital-based therapies are medically preferable in many instances, it is also generally conceded that their dominance in the U.K. is due more to the extreme pressures of ESRD cost-control imposed by years of chronic underfunding. In this context, the stress on nonhospital-based therapies, as one American analyst put it, "is simultaneously an escape from the small number of dialysis centers and also a rationing mechanism, since only the 'best' of the terminally ill ESRD patients do well at home."

It is hardly surprising, then, that this emphasis upon less expensive nonhospital-based treatments is accompanied by a more generally selective approach toward treatment in general. Thus, in contrast to France, West Germany, and Italy, where in 1982 from 250 to 234.5 ESRD patients PMP were treated, in the U.K. only 159.8 were treated. And while those countries admitted from 47.3 to 37.9 new patients PMP to treatment in 1982, the U.K. added only 29.5, a rate exceeded by the poorer Spain and virtually equalled by the far poorer Portugal and Greece (Broyer et al. 1984, 8).

The burden of the U.K.'s low treatment rates falls almost entirely upon those over age 45 or suffering from complicating diseases (like diabetes), for these kinds of patients are ordinarily considered less suitable for transplantation and home dialysis. There are also marked discrepancies among the regions—North West Thames, for example, treats patients at almost three times the rate of Wessex—and a common if unsubstantiated belief that the lower classes are disadvantaged, in that home dialysis places a premium upon certain middle-class attributes, like education and self-discipline (Fox 1975, 710; Simmons 1979, 202; Bryan 1981, 412).

The Office of Population Censuses and Surveys (1983, 38) reports that well over 3,000 persons die from ESRD in England and Wales each year and that another 2,000 die from unspecified renal failure, which is almost certainly very largely ESRD. It is generally conceded, however, that death from ESRD is frequently—perhaps, usually—asccribed to some more proximate cause, like ischemic heart disease, cerebral hemorrhage, or pulmonary infection. "Death certification," as one nephrologist put it, "is notoriously unreliable as a source of . . . data." True ESRD mortality rates are unknown, then, though they clearly far exceed official figures.

Macroallocation: How Society Assigns Resources

Virtually all patients in the U.K. suffering from ESRD are wholly dependent upon the National Health Service (NHS), a comprehensive, centrally financed health care system that provides for the entire population with little or no charge at the point of service. It is the NHS that, at least ostensibly, is in command of the macroallocation of health resources.

Despite the apparent primacy of the NHS and its parent organization, the DHSS, the ESRD treatment pattern in the U.K. does not derive from a formal national policy, which in an explicit sense simply does not exist. This is not, however, to deny the central office a major policy role, particularly in the early 1960s when the new ESRD technologies were developing and gaining acceptance.

Most important was the spectacular development of dialysis, which created, as one official of the Ministry of Health (the DHSS's predecessor), who observed matters at first hand, put it, "intense pressure to provide this life-saving measure" (Dennis 1971, 144). At the same time, however, the Ministry saw that if not carefully controlled, dialysis (and transplantation) could become a bureaucrat's nightmare. For it was immediately apparent to the Ministry's sophisticated civil servants that the new technologies combined three incendiary ingredients: they were fairly reliable, they were lifesaving, and they were expensive. If they had incorporated only two of these characteristics, no great problem would have been posed. If, for example, they had been reliable and lifesaving but not expensive (like, say, the Heimlich maneuver), they might have been adopted without frightening allocative consequences. Or if they had been lifesaving and expensive but not reliable (like heart transplants), they might have been assigned a low priority. Or if they had been reliable and expensive but not lifesaving (like cosmetic face-lifts), they might simply have been put aside as a luxury. But dialysis and transplantation each had all three qualities.

It was probably equally obvious to the Ministry that in an era of rapid advances in medical technology that tend to generate a "technological imperative" to use them (Mechanic 1979), dialysis and transplantation would before long be joined by other therapies that would also be reliable, lifesaving, and expensive, and have their own articulate advocates (see, e.g., Sherlock 1983; Timmins 1983). The new renal technologies, therefore, could not be viewed in isolation,

but rather had to be seen as prototypes of a new kind of treatment that would threaten existing financial patterns, even as it provided hope to patients and their families.

How was the Ministry of Health to respond? The new technologies seemed both too valuable to ignore and too costly to embrace. The answer plainly was a policy lying somewhere between these two poles. Since the Ministry was perennially short of funds, was at this time dominated by "an ideology of efficiency" (Klein 1983, 64), and could hardly have welcomed the prospect of reallocation that a major ESRD effort would have involved, the policy it chose did not lie exactly halfway between the two extremes. Instead, the decision was for an understandably rather cautious beginning, coupled with no firm commitments about the future.

Talk of cost-effectiveness, however, would not suffice to sell such a limited program to the medical community nor to deflect any outrage that might later come from the media, members of Parliament, or others. What was required was a medical legitimation of the program. It was at this point that physicians' committees, chiefly drawn from the Royal College of Physicians, were activated. Pragmatic types socialized into understanding NHS reality and eager to get the program going, the committees' members shared the Ministry's assumption of a modest beginning and gave most of their attention to practical suggestions. Cumulatively, they knew these suggestions could help to determine the success of the program, and if the committees did not focus upon such matters, they would have to be left to mere trial and error, with all the possibilities of needless death and suffering and avoidable budgetary retaliation that that might entail.

But because these physicians tended to view their task in narrow terms, to see themselves as team players, and to be preoccupied with quality to the virtual exclusion of quantity, they were easy for Ministry bureaucrats to use. For the physicians did not have to be manipulated; it was enough to appeal to their highest sentiments. Less eminent or more egalitarian physicians might have been more concerned with the eventual size of the program, it is true. Yet it is impossible to fault the physicians' integrity and even difficult to quarrel with assertions that no ironclad bureaucratic commitments on expansion would have been forthcoming in any case—nor would they necessarily have been kept, if made. In any event, it must certainly have been entirely predictable that distinguished physicians committees (i.e., drawn from

physicians at teaching hospitals) would be far more sensitive to creating renal units at centers of excellence (i.e., at teaching hospitals) than expanding treatment patterns to cover underserved portions of the population. Certainly, the relatively few teaching hospitals had become accustomed to a status even more favorable than that enjoyed by their counterparts in the United States. It was this quite limited approach that was initially recommended.

Once its macroallocative decision had received the imprimatur of the medical elite, the Ministry assented to what it had helped to bring about. Implementation, which in other contexts is often problematical (Pressman and Wildavsky 1973), raised no difficulties here, for in the name of spurring the establishment of the centers, the Ministry retained control over renal unit financing during the early stage. And after the units were turned over to the regions in 1971, unwanted expansion of treatment patterns was avoided by the simple expedient of not providing special funding for that purpose. Congenitally strapped for funds, the regions were hardly in a position to proliferate renal units. Thus, the Ministry's initial decision to limit ESRD treatment could retain its force, even after the units themselves had come under other structures' jurisdiction.

Making this rather strict financial discipline possible is the long-established U.K. practice of setting and adhering to definite budget allocations. In the United States, by contrast, budget allotments tend to be mere projections, which all interested parties understand will be supplemented when they are exhausted. While United States policy makers know only with hindsight what they have spent, therefore, U.K. officials have a clear idea before the fact.

What the regions have done over the past dozen years or so is to have responded to their evolving environments in a classically incrementalist fashion, eschewing what one regional officer termed "big picture" policy making and generally carrying over funding levels with only marginal increases. To "men in the middle," as one regional officer called himself and his colleagues, such an approach is apt to appear the only one that makes sense.

On the one hand, that is, regional officers tend to feel besieged by requests from districts and regional specialities (like renal services) to remedy long lists of deficiencies. Nearly always, of course, the extent of the deficiencies is exaggerated, and yet that serious deficiencies exist is beyond question. On the other hand, however, regional officers

complain that the system consigns them to abandonment by their superiors at the central office, who are required neither to offer clear guidance to the regions nor to take public responsibility for unpopular decisions. Left to confront the cacophony of demands unprotected, regional officers are naturally reluctant to overturn settled relationships and long-held expectations. ESRD treatment patterns, as a result, seem relatively secure from serious retrenchment. By the same token, though, since greatly expanding these patterns could be accomplished only at the expense of some other claimant, the same fear of upsetting a liveable arrangement that protects ESRD also protects its rivals and prevents the program from growing dramatically. Thus, ESRD treatment patterns have grown only gradually since 1971 at about 8 percent per year, compounded annually. The DHSS, meanwhile, in complete harmony with its parliamentary mandate, has justified its abdication by reference to maximizing responsiveness to regions and districts.

ESRD Disadvantages

To this situation of institutionalized, almost genetically based caution, ESRD brings several important disadvantages. First of all, relative to the treatment modalities of most other diseases, ESRD has a rather unusual mix of capital and labor costs. On the one hand, it is much more capital intensive, especially when dialysis machines are involved; on the other hand, it is much less labor intensive, especially when home-based therapies in effect enroll the patient and his family as unpaid employees of the NHS. ESRD therapies, therefore, entail only modest staffing. One result is that there are relatively few personnel to press for expansion or oppose retrenchment. Another is that funding cutbacks produce only a small number of layoffs, a situation administrators greatly prefer. The temptation for policy makers to resist increased ESRD funding, as a consequence, is ever present.

Second, in recent years, the general thrust of DHSS efforts has been to shift "expenditures away from hospitals and toward general medicine and community health activities" (Ham 1982, 29). On one side, bureaucrats and reformers have argued that greater funding for the so-called "Cinderella services" for the mentally ill, the handicapped, and the aged is required both by cost-effectiveness and simple justice (Department of Health and Social Security 1976). Hospital consultants, with their natural preference for acute care, have resisted this trend.

Despite the consultants' efforts, however, a change in emphasis has clearly taken place.

This newer emphasis can only buttress ongoing ESRD treatment patterns, which have stressed less expensive, nonhospital-based therapies for many years. Any effort significantly to expand treatment patterns—which, it is assumed, can be accomplished only by increasing the number of patients dialyzed in hospitals or centers—must collide with this more fashionable approach, perhaps appearing hopelessly out of date.

Third, the expensiveness of ESRD treatment raises questions about the individual's right to health care that do not emerge with comparable impact in most other conditions. This is not the place to rehearse the familiar ethical arguments, pro and con. They have been addressed at great length in appropriate forums (e.g., Rescher 1969; Katz and Capron 1975; Almeder 1979; Winslow 1982), and doubtless will be discussed at even greater length in the future. It is enough to say here that in the U.K. it has traditionally been accepted that, in the words of Guido Pincherle, a DHSS senior medical advisor, "there is no right to treatment" (Parsons and Ogg 1983a, 113).

In West Germany, France, Italy, and Spain, on the other hand, ESRD treatment is funded through insurance schemes, and so the ruling assumption is that the patient is entitled to whatever treatment is medically indicated. The United States, which funds ESRD treatment under Medicare, has taken essentially the same view, though a number of significant costs are not covered (Campbell and Campbell 1978; Greenberg 1978).

The notion 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 that is looked to as the chief 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. The fear of treating too many, in short, inspired much more passion than the fear of treating too few.

It would be too facile, however, to attribute this attitude simply to America's greater wealth, for what is involved are also certain

highly pertinent choices. If the British have been rather parsimonious with the NHS, in other words, this partially reflects decisions taken after the war to allocate large sums on schools, housing, and social services; even as Tocqueville noted ([1840] 1961, 153–55), Americans put unusual value on health. Equally, perhaps, the U.K. practice may stem from an almost reflexive horror of welfare state extravagance. “Value for money” is a phrase a visitor soon learns, and “value” here implies a reasonable return not only to the patient but also to the public. This attitude, embedded long ago in the notorious Elizabethan Poor Laws, lies near the core of the benevolent NHS, too. The present reluctance to dialyze older ESRD patients, for example, finds a clear parallel in the late 1950s, when full rehabilitation services were offered pretty much only to those under age 65 (with first priority to those under age 50 or 55), to those with a prior history of gainful employment, and to those for whom reemployment was certain. Similarly, cataract surgery for a while was also restricted to patients under age 65. Given this tradition and what has become an almost universal pessimism regarding a near-term end to significant scarcity in Britain, the ESRD budgetary restraints must have seemed not only sensible but necessary—and in a patently obvious way.

Fourth, ESRD treatment is not a curative, “one off” affair, but instead involves a heavy continuing commitment for the rest of the patient’s life, often for well over a decade. Hospital dialysis, of course, is especially costly, but even a successful transplant is not cheap. Each ESRD patient, therefore, must be viewed financially as a potential consumer of tens of thousands of pounds, not to mention the time and energy of innumerable physicians, nurses, counselors, and other staff. Thus, unlike, say, the polio vaccine, ESRD treatments do not relieve the health system, but rather add to its cumulative burden.

What this means for ESRD patients collectively is that each year’s budget allocations must not only cover the costs of adding new patients, presumably at least at the ongoing rate; they must also pay for the continuing costs of the patients already receiving treatment, less the relatively small number who have died during the past year. Thus, even if there were no inflation, the costs of maintaining the program at a constant level would entail significant annual increases. When inflation and a desire to expand the program are added, the annual increases become even greater.

Of course, technical cost-cutting breakthroughs are always possible.

Indeed, in the early 1970s in the United States it was widely believed that such breakthroughs would soon render transplantation both much less costly and much less risky, thereby permitting virtually all persons who required ESRD therapies to be treated at a fairly moderate aggregate cost (Scribner 1971). The breakthroughs, however, never fully materialized, and the cost of the American program now approaches \$2 billion per year; that is, less than 0.2 per cent of the Medicare population accounts for over 5 per cent of the Medicare budget. What had seemed merely optimistic in hindsight is revealed as wishful thinking.

Fifth, the very uncommonness of ESRD hampers attempts to increase funding, and not simply because it limits the political attractiveness of the effort. For the chief goal of the NHS, equity in health care distribution, in practice has really meant a commitment to providing minimum adequate levels of care, with "minimum" defined as the "services that most people use most of the time" (Abel-Smith 1978, 19). ESRD, of course, does not fit comfortably in such an approach: it afflicts too few persons and its costliness is seen as intruding upon the resource base required to fund minimum care levels for far larger populations. ESRD demands that will seem barely adequate to some, therefore, will always appear clearly excessive to others.

Sixth (though the implication of this point is disputed), ESRD treatment has been more thoroughly quantified demographically and "costed out" financially than treatment for almost any other condition in the U.K. (Laing 1979, 113), principally as a result of efforts from renal physicians themselves.

Nearly all ESRD treatment advocates appear to believe, however, that these efforts have proved counterproductive (e.g., Robinson 1978, 17). When they decry physicians spending large sums on hopeless cancer patients (e.g., A. J. Wing in *London Times* 1981; W. R. Cattell in Parsons and Ogg 1983c, 53-54), for example, they are fully aware that their evidence is almost entirely anecdotal, and thus that their assertions that ESRD treatment deserves priority over these procedures may have a self-serving, unpersuasive ring.

On the other hand, it must be noted that ESRD treatments have not been costed out all that well. Estimates have varied widely, apparently reflecting not only differentials in expenses but also in actual methods of calculation. There is no consensus, for example, on how to deal with patients who move from one therapy to another or

with medical complications that may accompany treatment or whether transplantation should be discounted by a "quality-of-life" factor (and if so, by how much). Nor has a nationwide analysis been performed. Certain other treatment strategies (e.g., minimum care "satellite" dialysis centers or simplified home dialysis systems) have not been costed out at all.

Despite these problems, the impression persists among all interested persons who were interviewed that ESRD treatment is well costed out. Acknowledging the problems, one regional administrator declared, "The NHS costing system is primitive in the extreme, but it is better for renal services than for nearly any other area." The contrast to coronary artery bypass surgery, where comparable data are said to be simply unavailable, was often noted.

The same regional administrator went on to say, however, that ESRD treatment advocates were quite mistaken if they imagined that their costing data weakened them in the scramble for resources. On the contrary, he argued, "If you can quantify something, you're king. The act of putting figures on a proposal gives it power." For regional officers, particularly treasurers, tend to be very suspicious of vague and unsubstantiated claims.

Taking the U.K. as a whole, however, it is impossible to say whether ESRD costing data harm treatment advocates (as they contend) or help them (as the regional administrator quoted above believes). The answer may even vary from region to region and time to time.

In its favor, ESRD treatment advocates can, in the last analysis, point only to a single factor, though in a society ostensibly committed to maximizing social welfare it is one of some potency: the treatments can reliably extend useful life for thousands of persons. Obviously, this does not guarantee treatment advocates budgetary success, but it does guarantee them a hearing and makes the issue impossible completely to ignore.

Cumulatively, however, so powerful have these forces for caution been that neither media attention nor patients groups' advocacy nor nephrologists' agitation nor even politicians' diatribes have made much of an impact upon the prevailing rate of incremental change in treatment patterns. This is not to say, of course, that incrementalism has precluded change. On the contrary, more ESRD patients are treated today in the U.K. than ever before.

Yet, it is equally clear that "change" has not meant "something

new”; it has meant “a little more.” In a medical scientific setting, such an outlook may well strike the observer as jarring, for science suggests a willingness to alter direction that the incrementalist can scarcely imagine. Some scientific advances can be accommodated by incrementalism, of course, such as the forearm catheter or CAPD. But that is not merely because they were improvements over what had gone on before; it is also because their acceptance involved no departure from incrementalist resource growth. Other scientific findings—that vastly more than 40 new patients PMP can be treated each year and that home dialysis may be workable for nearly 90 percent of all patients (George 1983)—have been essentially ignored. This is not because they conflicted with earlier normative assumptions about patient quality of life, but instead because their adoption would entail at least a temporary rejection of incrementalism. It is this incrementalism, sustained by vast bureaucratic momentum and undeniable bureaucratic rationality, that those seeking major departures in ESRD treatment patterns must confront and conquer.

Speculations on the Bureaucracy

Over the years, it has proved difficult for extra-bureaucratic actors—whether politicians, physician or patient groups, the media, or public opinion—to force the bureaucracy to do anything it does not want to do regarding ESRD treatment. It is true that the bureaucracy did not bring the new technologies into being (nor could it wish them away, even if it wanted to). Yet, it is also true that the bureaucracy orchestrated their introduction and has effectively controlled their growth. Those interested in coercing policy makers lack the power, and those possessing the power lack the interest. What this suggests is that the policy makers’ own values, goals, and beliefs are probably of central importance in understanding their behavior. The analyst must proceed with caution here, of course, for hard data are absent, impressions can mislead, and speculation can be treacherous.

Nevertheless, the observer is left feeling that policy makers are of two minds on the question of ESRD treatment (cf., Downs 1967, chap. 8). First, as officers in the proudest institution of the British welfare state, they appear, at least in part, to be driven by compassionate concerns. This is one reason they entered the Health Service to begin with, and not some other line of work. Time and again, policy makers

volunteered that the NHS was not doing enough for ESRD patients, and though efforts were made to stress the pattern of improvement or to blame the shortfalls on others, no one indicated that he considered the policies adequate. Typical, perhaps, was the remark of a DHSS official who, on hearing praise of the cost-effectiveness of ESRD treatment patterns, remarked ironically, "Death is cheap."

This sense of compassion, perhaps in truth an amalgam of guilt and shame, is reinforced by a number of extra-bureaucratic actors: patients' groups, renal physicians, the media, and so on. Given the nature of the kind of people the Health Service recruits, these feelings would probably be present anyway. Still, outside actors collectively may be significant in strengthening these feelings or at least in preventing their erosion.

Second, as officers in an institution, the policy makers are, above all, bureaucrats. As such, they are driven by bureaucratic ideals (like efficiency), they think in bureaucratic terms (focusing upon abstract collectivities rather than suffering individuals), and they respond to bureaucratic imperatives (such as avoiding upsetting settled relationships and standard operating procedures).

In this regard, it is important to note that despite its compassionate rationale, the NHS was not a product of a paroxysm of altruism, political radicalism, or working-class struggle. Instead, as a Marxist critic acknowledged, "The state was responding to the organizational and fiscal problems within the health sector and . . . was seeking to create a rational, efficient, nationally coordinated health service" (Walters 1980, 156). By the end of the war, that is, almost no one believed that the nation's jerrybuilt health system should be left unchanged to confront the next rush of problems. It was this conviction that led to the creation of the NHS, a creation brought about by what one analyst aptly called the "paternalistic rationalists within the civil service and the medical technocrats [who] sought to maximize the opportunities to deploy the tools of medical science" (Klein 1983, 25; 1984, 84–87). Ideologues and politicians played a relatively minor role.

How to resolve the dissonance struck by the compassionate and bureaucratic themes? Incrementalism provides a workable response, for it obviates the necessity of making the difficult choice. Instead, all that is required is to continue on the path others had earlier marked out. Of course, initially a choice had had to be made—in ESRD as

with so many others, it was an obvious compromise between competing approaches—but that was long ago. Once made, it need not be reexamined but merely (with gradual alterations) repeated. For if incrementalism does not exactly permit conflict to be avoided, it does minimize its pain and discomfort.

Microallocation: How Patients Are Selected for Treatment

The importance of the microallocative level is directly attributable to the macroallocative patterns that have emerged. If sufficient resources had been provided to treat virtually all ESRD patients, as in the United States, the microallocative decision as to whether to treat would have long since faded away, like the background in an old snapshot. Because such resources have not been made available—because, indeed, a condition of hyperscarcity has prevailed from the outset—the microallocative decision has retained immense significance and continues to raise a number of rather disturbing issues.

In the microallocative decision as to which ESRD patients are to receive treatment, the key actors are the patient, his general practitioner and general medicine hospital consultant, and his nephrologist.

The Patient

The patient's importance, it must be said at the outset, lies almost entirely in his condition and rarely is a function of effective efforts on his part to influence outcomes. Partly, this may simply be a function of the nature of most health care in advanced societies. Health care, of course, is unusual in that after the initial patient decision to see a physician, it is producers who determine demand far more than consumers. In the first place, that is, it is normally the physician who determines whether and what tests, drugs, surgery, and so forth are required by the patient, not the patient himself.

More than that, it is a producers' elite that helps to shape the working physicians' demands. These are the individuals who are invariably given credit: Scribner and his associates (Quinton, Dillard, and Scribner 1960), who made dialysis a viable treatment for ESRD; Cimino and Brescia (1966), whose forearm fistula made the procedure capable of many more repetitions; Tenckhoff and Schechter (1968),

whose improved catheter made CAPD feasible; and so on. The patient's inarticulate plea to "help me," in other words, would remain a mere pitiful noise without innovators to create the technological possibility to help and without physicians to utilize that technology actually to help. The innovators saw a need and responded to it, and so did the physicians; the patients benefit from the technology but do not bring it into being or apply it to individuals, though their compliance with physicians' instructions (particularly, if they dialyze at home) does make them, in a sense, junior partners in the implementation of treatment.

Partly, also, the patient's relative unimportance may reflect the physician's natural dominance, commonly attributed to his vast advantages in knowledge, skills, and experience and to the potent scientific life-or-death mystique surrounding his role. There is some evidence that the traditionally passive British patients are more assertive and knowledgeable today than in the past, but the differences are small, and since the hospital specialist may be the most prestigious of professions, patient deference to him is likely to be very great indeed (Cartwright and Anderson 1981, 115, 186; Schwartz and Aaron 1984, 56). ESRD patients, often fatigued, confused, and vulnerable, may seem particularly helpless and aware of their own dependency and limitations.

Partly, too, as several physicians who were interviewed suggested, the passivity of the patient may be a function of the more general British deference to official authority. "The English tend to be rather docile," as one consultant phrased it. Another spoke of the "British quality of 'up-puttingness'" (i.e., the predilection for putting up with adversity and viewing complaining as bad form). This, he felt, was reinforced by a "rather stratified class structure" that in the medical context encourages the belief that the "doctor knows best." Similarly, other doctors interviewed observed that though when patients complained about the decision not to treat, the decision was sometimes reversed, the overwhelming proportion of patients denied treatment simply acquiesced without protest (cf., Schwartz and Aaron 1984, 56).

Clearly, however, it would be a mistake to exaggerate the extent of this docility; the U.K. is a nation not only of considerable class deference but also of class conflict, and the modern history of the society could not be told without reference to the rise of the Labour

Party, the actions of militant trades unions, the intellectual generation of *Look Back in Anger*, the persistent disaffection of significant strata of the youth, and so on (Hart 1978, 193–202; Kavanaugh 1980, 156–58; Beer 1982, chap. 4). Yet the sheer, almost overwhelming stability of the U.K. certainly suggests that respect for authority has long been a potent factor.

The relative passivity of U.K. patients may also be traced to a greater capacity to cope with pain and discomfort. Less likely to complain, they may be more likely to accept both their illness and their physician's decision as to what ought to be done about it (though not focusing upon ESRD, see Zborowski 1952; Sternbach and Tursky 1965; Zola 1966; but cf., Koopman, Eisenthal, and Stoeckle 1984).

Additionally, the patients' passivity appears to be accentuated by certain structural constraints built into the National Health Service; for they cannot consult a specialist on their own but only upon a specific referral from their general practitioner. And if the general practitioner concludes that a specialist is required, he selects the specialist. In such a context, the patients' passivity can be said to be one of the system's ruling assumptions, for if dissatisfied, they may perceive their options as exceedingly limited. They can accept their lot, perhaps grumbling to themselves about their bad luck. Or they can complain to their general practitioner, risking alienating him during this time of crisis. Or they can try to replace their general practitioner, a task entailing obtaining permission from their local Family Practitioner Committee and then finding a new general practitioner who will accept them. But though Family Practitioner Committees usually grant permission, their involvement ordinarily is so intimidating and time consuming that most patients are deterred from this option—and for those patients not so deterred, the difficult job of securing another, more compliant general practitioner is a prospect sufficient to scare most of them. Patient "shopping around" for physicians that is so widespread in the United States is far less common in the U.K., where convenience and tradition rather than medical evaluation tend to determine the patient's choice of a general practitioner. Usually, in fact, the British patient does not even perceive a choice to be made; either he knows no other doctor or has no reason to believe that a change would bring an improvement. It is hardly surprising, then, that only 4 percent of patients surveyed in 1977 had changed

general practitioners as a result of dissatisfaction (Cartwright and Anderson 1981, 8).

The General Practitioner

Far more important than the patient as a microallocative actor is his general practitioner. It is his responsibility to reach a preliminary diagnosis and to decide whether the patient should be sent on either to a nephrologist or, as is more often the case, to a general medicine department at a local hospital, which may then refer the patient to a renal unit.

The general practitioner's significance, therefore, is more commonly negative than positive; by misdiagnosing or deciding against referral, he effectively closes the door to treatment, while by sending the patient to a nephrologist or a general medicine department, he merely passes the decision onto a higher level. His relative inexperience with ESRD, however, may hamper his efforts, for many general practitioners identify only a single case every ten years (Parsons, in Parsons and Ogg 1983b, 245), and most lack all ties with nephrologists and are without personal access to the biochemical facilities that ESRD diagnosis requires. General practitioners may also be quite unacquainted with prevailing treatment patterns, and fail to refer patients for reasons that have long since become procedurally obsolete. Thus, one general practitioner, when presented with sixteen hypothetical cases, observed ruefully that "under present circumstances probably none would be accepted" for treatment (Challah et al. 1984, 1122), though such extreme resource scarcity had not existed for many years. No wonder that among nephrologists, general practitioner apathy and ignorance concerning ESRD is proverbial (e.g., Little, Cattell, and Dowie, in Parsons and Ogg 1983b, 242-43).

Although the general practitioner may reject referral for treatment of some ESRD patients, this negative decision is more likely to be made by a general medicine consultant from a nearby hospital (Challah et al. 1984, 1120). The consultant, however, typically has "limited experience in renal medicine" (Gabriel 1983, 36), and may be prone to make referral decisions on moral or other nonmedical grounds. "I have always referred on merit," one consultant reported, "but I have made the value judgment as to who is meritorious myself" (Challah

et al. 1984, 1122). There is also reason to believe that out-of-date clinical selection criteria may sometimes be used. As one nephrologist put it, "New developments have not really percolated to the consultant level," and so their practice tends to reflect what they learned a decade or more earlier. But since the patient cannot ordinarily see the nephrologist on his own, it is frequently the view of the general medicine consultant that prevails (cf., Chantler, paraphrased by Lupton 1979, 3–4).

Both the general practitioner and the general medicine consultant, then, illustrate some of the strengths and weaknesses of the so-called "gatekeeper" approach to medical cost-containment. On the one hand, by minimizing the role of the specialist, the more expensive styles of practicing medicine are restrained. Costs, as a result, certainly are kept down. On the other hand, however, some medical decisions that might better be made by specialists are left to physicians with less relevant expertise and experience. The problem, of course, is exacerbated if the physician is overloaded with patients or is the kind of doctor who requires external stimulation (competition, colleague pressure, etc.) to keep current and provide personalized service. For a comprehensive, taxpayer-supported system like the NHS, the cost-containment imperative probably will always dominate. Nonetheless, as the case of ESRD demonstrates, there are medical costs in ascribing the gatekeeper role to nonspecialists, and these costs are borne primarily by the patient.

The Nephrologist

It is with the third actor, the nephrologist, that the most carefully considered microallocative decision ordinarily rests. His decision context, to be sure, may be far from ideal. The nature of renal failure is such that symptoms are not usually reported until the disease has progressed quite far, and referral procedures may sometimes add to the delay. As a consequence, by the time the nephrologist sees the patient, it may be "too late for there to be time for a carefully considered plan of investigation leading to a carefully constructed strategy for treatment" (Knapp 1982, 484). It may even in some rare cases be "too late to treat the patient at all" (*British Medical Journal* 1978, 1449).

Whether confronted in an optimal context or not, the decision as

to treatment must be made. How is it reached? The usual answer given by physicians—general practitioners, general medicine consultants, or nephrologists—is that it is a clinical judgment found by applying sound medical criteria to the individual patient's case. These criteria are not always clearly spelled out, but generally seem to entail at least an implicit calculation of the probability that the treatment will succeed and, if successful, that the patient could then expect a satisfactory quality of life. Thus, the physician asks, for example, whether the patient is otherwise healthy or suffers from a complicating illness; or whether he is psychologically able to cope with the stress the treatment will impose or is likely to fail to comply adequately with the prescribed regimen or even to drop out of the treatment program entirely.

Despite the apparent straightforward reasonableness of such questions, however, the exclusive emphasis upon the medical character of patient selection appears undermined by several major problems. The first is that physicians' clinical judgments need not agree with one another. Error and disagreements regarding observations and evaluations are hardly unique to ESRD (see, e.g., Graham, de Dombal, and Goligher 1971; Bennett 1979, 165–75). In ESRD cases, though, there is evidence that the extent of the disagreement may be quite astonishing. In one study, for example, 25 British nephrologists were asked to reject 10 out of 40 hypothetical ESRD "patients." Only 13 "patients" received unanimous judgments—all acceptances—and 6 of the "patients" most frequently rejected were actually modeled after real patients who had been successfully treated (Parsons and Lock 1980). Similarly, in another study, 8 Glasgow clinicians in a renal unit were asked to classify the suitability of 100 hypothetical ESRD "patients" for treatment; in only 32 cases did the physicians all agree either to treat or not to treat the patients (Taylor et al. 1975).

Moreover, different physicians apparently rely upon different key indicators to aid their judgments. Some physicians, for instance, may predict medical outcomes on the basis of early patient reactions to dietary restrictions (Czaczkes and Kaplan De-Nour 1978, 154–56); others report this to be of little help (Robinson 1978, 16). Some may tend to turn away diabetics (Medical Services Study Group of the Royal College of Physicians 1981, 285); others may accept them (Berger, Alpert, and Longnecker 1983; Legrain 1983). Some may be doubtful about treating children under age 5; others may treat infants (Trompeter et al. 1983; Hodson et al. 1978). Some may automatically

reject patients over age 65; others may treat those in their 80s (Chester et al. 1979) or even a senile patient of 90 (H. Gurland in *Controversies in Nephrology* 1979, 133). For certainty of death in the absence of treatment is countered by the uncertainty of the efficacy of treatment in specific cases. As one prominent nephrologist concluded, "When treatment is provided for patients with an apparently poor prognosis, surprisingly often those expected to fare badly may do well. There are, in fact, few objective measurements to predict the response to treatment" (Knapp 1982, 848).

To some extent, these differences among physicians may reflect differences in levels of ability and conscientiousness. And as one analyst argued, "Although U.K. consultants have more freedom than most [specialists in other countries], they also are more isolated and have fewer means of knowing how their performance compares with others. . . . Consultants," he adds, "may be appointed at thirty-five and for the next thirty years have no real scrutiny of their work" (Dick 1983, 899).

More than this, however, differing medical judgments also flow from what one physician who was interviewed called the "inherent subjectivity" of the process. Though some patients clearly have excellent prognoses and others poor ones, a number of patients fall in the gray area in between. Whether they will be assigned to the "accept" or "reject" tracks are difficult, complex, problematical questions. In answering them, physicians naturally proceed analogically. That is, they compare the patient before them with similar patients they have treated, observed, or otherwise learned about through the literature or from colleagues. The physician assumes that identical patients with identical diseases will respond identically to identical therapies. But he knows, too, that in the real world "identical" is merely an analytical construct and that in the real world he must content himself with "similar." This realization, however, necessarily generates uncertainty: Is the patient before me, he must ask, so like another patient I am familiar with that I should treat him in the same way or so different that I should treat him in a different way—and if he is different, how different is he? To such questions, there may be several answers, for a single response is compelled neither by science nor by logic. Instead, reasonable, thoroughly competent physicians will differ, some stressing the similarities, others the differences. No unambiguous, objective methodology can be relied on to yield infallible answers.

Lacking such a methodology, physicians must be presumed to be influenced by their knowledge, experience, and training, and probably also by the prevailing practices at their hospitals, their own personalities, pressures from the patient's family, and any number of other factors which will be unique to each individual physician. Whatever the explanation, though, the data on physician disagreements on ESRD patients would seem to leave in tatters any pretense that the uttering of "clinical judgment" can banish doubts behind a curtain of consensus.

The Limitations of Clinical Judgment

Is "clinical judgment," then, uniquely subjective in cases of ESRD? Clearly not. All clinical judgments are, after all, *judgments*, a word that implies a recourse to a subjective best estimate. Moreover, since untreated chronic renal failure almost uniformly results in death, the consequences of a decision not to treat are quite predictable. This element of virtual certainty, however distressing, is lacking in the vast majority of other diseases. Furthermore, inasmuch as the U.K. nephrologist is not employed on a fee-for-service basis, he lacks the "personal financial incentive to treat more patients" (*British Medical Journal* 1978, 1449; Schwartz and Aaron 1984, 54), and thus may work with greater detachment than his colleagues in other countries. (It is easy to exaggerate the significance of this point; the financial is only one of a vast tangle of incentives and disincentives [see, e.g., Grist 1981]).

By the same token, however, it may be more difficult to forecast patient response to ESRD treatment than is true in many other diseases. For, to an uncommon degree, success depends not only upon physiological factors, but also upon psychological and even domestic factors. The physician's ability to predict the effects of these variables, let alone to influence them, may be much less than he would desire.

A second problem with an exclusive reliance upon clinical judgment is that many pertinent medical criteria that underlie it have not been systematically tested empirically. One pioneering figure in the development of home dialysis, for example, stressed the importance of the patient's being of average intelligence (Shaldon 1968a, 522). If he were below average, it was argued, he might be unable to learn and perform all his tasks; and if he were above average, he might have difficulty accepting his role and become extremely anxious. Pre-

sumably, some patients considered to be outside the intelligence limits were denied treatment on that account and consequently died. But was the hypothesis on intelligence ever tested? Was the intelligence of the patients precisely determined? Was intelligence itself, notoriously an ambiguous and vague concept, satisfactorily defined? The record is barren of answers.

Of course, the intelligence hypothesis appears plausible, but plausibility cannot be confused with confirmation, particularly when life or death decisions are being taken. Psychological denial, for example, may not at first glance seem a good predictor of successful patient adjustment to home dialysis, but, by inducing patients to see themselves as only marginally ill and thus quite able to resume their normal roles, it is (Glassman and Siegel 1970; Short and Wilson 1969; Richmond et al. 1982).

Some hypotheses, though, lack even surface plausibility. In the early years of dialysis, for example, one of the most widely respected of U.K. nephrologists assured his colleagues that “gainful employment in a well-chosen occupation is necessary to achieve the best results” in hemodialysis, since “only the minority wish to live on charity” (Parsons 1967, 623). This extraordinary proposition—that the unemployed make poor patients because most would literally rather die than become public charges—was simply announced, despite the fact that large numbers of dialysis patients have always found the treatment too debilitating or time consuming to permit them to work.

A third problem is that medical criteria incorporated into the judgment process often become entangled with clearly nonmedical considerations. Another major pioneering nephrologist, for instance, declared that in selecting patients for dialysis, preference would be given not only to those with “the qualities of reliability, common sense, and stoicism”—all of which arguably would increase the likelihood of successful treatment—but also to patients with young children (Ogg 1970, 412). This consideration bears on the worthiness of the patient to receive treatment, and is really not medical in character at all. While physicians may for good and obvious reasons claim authority to devise and apply medical criteria, however, their nonmedical judgments would not appear to deserve special weight. Indeed, given what one philosopher of medicine who was interviewed characterized as the average physician’s rather shallow acquaintance with systematic work

in medical ethics, his implicit assumption of competence in this area must strike some observers as deeply disturbing.

A fourth problem with an exclusive reliance upon clinical judgment is that even if the first three problems were to vanish, the number of patients deemed medically suitable for treatment would substantially exceed the number whom the system could accommodate (but cf., Medical Services Study Group of the Royal College of Physicians 1981; Abram and Wadlington 1968). In such a situation, what should the physician do? The platitudinous reply (drawn here from a non-ESRD context) is that the "individual physician in his effort to save the individual patient, cannot, and cannot be expected to, consider the allocation of resources" (Bendixen 1977, 383; Beauchamp and Childress 1979, 195; Hiatt 1975, 235–41).

But if this represents the ideal, the real world extorts the precise opposite answer: "What constitutes 'good' medical practice and 'right' clinical decision will be determined by cost-effective analysis as well as by scientific correctness and by humanitarian content" (Wing 1979, 152). With this in mind, two doctors deplored "the extent to which physicians' professional expertise and position of trust is being used to translate economic and political decisions into the selection of patients, without those presenting with renal disease, their relatives or the public necessarily being aware of the process" (Parsons and Lock 1980, 175). The *Lancet* (1981, 595) echoed this conclusion, editorializing, "Economic necessity dictates clinical decisions but is not always seen to do so."

Even if, for the sake of argument, we assume that wholly objective medical criteria simply await the physician's automatic application, a larger question persists: Ought medical criteria to be the only legitimate criteria utilized in patient selection? In the U.K., the prevailing answer is clearly "yes." As one distinguished nephrologist put it, "If we cannot treat all, then those left to die will be chosen because, in the opinion of doctors, they are likely to do less well on treatment than others" (Wing 1979, 163). Though some dispute may attach to the nature and application of these medical criteria, almost no one dissents from the proposition that medical criteria are the best (if not the only) guide to patient selection. The sole criticism emanating from the medical community would seem to be that implementation of the ideal has been, like all human endeavors, imperfect.

It is not difficult to speculate as to why such a view should have become so universal. After all, physicians make the actual choices, and their authority and expertise extend only to medical matters. Moreover, to speak exclusively of medical criteria is to suggest to the lay public an objective, rather mechanical reasoning procedure, whose very impersonality may seem a reassuring protection against favoritism and abuse. Of course, this view may be quite naive and misleading, but it is no less widespread for that.

Yet, the judgment that only medical criteria should be applied is also a normative judgment. It is true, of course, that treating only patients with the best prognoses is the most efficient use of scarce resources; more patients per unit of resources can be treated in this way than in any alternative approach. Some observers might retort, however, that efficiency is not the highest value. Ought dialyzing ten Antonio Salieris be preferred to five Amadeus Mozarts merely because the Salieris have better prognoses? Upon such questions, the consensus supporting exclusive reliance upon medical criteria must founder. Even physicians appear on occasion to share this kind of reservation. When one consultant wrote that "one would have to rank on the positive side—ability to help the community by working" (Challah et al. 1984, 1122), he was clearly uttering an ethical, not a clinical judgment.

The problem is that, to the extent that microallocative decisions reflect macroallocations, they are true tragic choices (Calabresi and Bobbitt 1978). Society spares only some ESRD patients from suffering and death, finds it awkward to face the fact of its abandoning many helpless and blameless citizens, and prefers that physicians make the selections according to their own divinations—and do so privately. Medical criteria, if they were widely discussed, doubtlessly could be revealed as inadequate, but it is the nature of tragic choices that no criteria can receive near universal acceptance. However much a detached analyst may deplore it, therefore, there may be an irresistible tendency to transmute certain kinds of normative decisions about resources into technical decisions about treatment. "Human kind cannot bear very much reality" (Eliot 1958, 118).

If the prime victims of these microallocative pressures are the ESRD patients, hyperscarcity takes a heavy toll from nephrologists and other medical personnel, as well. For the process of selection, according to some observers, forces physicians to act as judges, sometimes in the face of fears about their own imperfect knowledge and objectivity.

Rejecting patients desiring treatment may be particularly difficult, as it may seem contrary to the physicians' medical training and to the ethic of the welfare state into which they have been socialized. That the nephrologist ordinarily makes the decision alone (though typically after consultation with other members of his renal unit) also makes for a certain stressful ambivalence; an unconscious wish for omnipotence may produce some enjoyment from the exercise of power, while the decision to say no may generate feelings of guilt often accompanied by an emotional withdrawal from the patients under care (Kaplan De-Nour and Czaczkes 1968; Shaldon 1968b). Such feelings are probably not uncommon among all kinds of physicians responsible for the long-term care of patients with potentially fatal diseases.

On the other hand, another observer, who for many years has been committed to viewing patient selection from the patient's viewpoint, claimed that a more ominous development was more typical. At the beginning, she said, young physicians were "appalled" at letting treatable patients die; after a while, "they learn to stomach it"; within a couple of years, it had "become part of their lives," an accepted element in the routine. In this sense, she argued, most participating physicians may be compared to the "good Germans," who gradually accommodated themselves to the "final solution" and whose active cooperation in the annihilation of much of European Jewry was essential to the success of the enterprise. Far from being burdened with guilt, the physician, in order to cope with the perceived necessity of rejecting treatable patients, instead hardens his heart, she maintains. Meanwhile, easing the doctor's rejection decision somewhat is the "clinical myth" that renal failure "is a pleasant way to die" (Knapp 1982, 847; Challah et al. 1984, 1122; but cf. Roher 1959).

Yet even this view must find a place for the terrible anguish repeatedly and publicly expressed by many of the U.K.'s leading nephrologists. Unwilling simply to exit and make a bad situation worse, a number have given voice to their frustration over macroallocation in an effort that outsiders can only find moving and heroic (cf. Hirschmann 1970).

For others, however, the prospect of becoming or remaining a nephrologist in the U.K. evidently seems simply too daunting. Thus, while in Italy there are 2,500 accredited nephrologists, in the U.K. there are only 117 senior and 207 junior staff (Royal College of Physicians, College Committee on Renal Disease, Executive Committee

of the Renal Association 1983, tables 1-2). Constricted opportunities arising from budgetary restraints, furthermore, may also be contributing to the fact that, among new physicians, only 0.1 percent list nephrology as their first choice and only 0.2 percent as their second or third choice (Parkhouse et al. 1983). Nor is the impact confined only to physicians. For the paucity of dialysis centers has sometimes led to very tightly packed dialysis schedules and very heavy workloads for the support staff; this, in turn, has resulted in difficulty in obtaining and keeping staff (McGeown 1978, 418; more generally, Kaplan De-Nour 1984).

The picture that emerges is of a physician whose theoretical autonomy—constrained only by sound medical considerations and legal and contractual obligations—is seriously limited by practical considerations. He routinely prefers nonhospital-based therapies not because they are necessarily superior, but because their lower cost renders them the only ones available. As a consequence, some patients will receive optimal treatment, some suboptimal, and some none at all.

In this, the physician is not submitting to cynicism. On the contrary, he is likely to be acting in what he himself perceives as a highly ethical manner. But it is a hard-headed utilitarian ethic of choosing to treat many low-cost patients, rather than fewer high-cost ones.

Medical and Political Roles in Conflict

The physician, however, is not merely a philosopher, declaring and defending certain ethical preferences. He is also an actor with dual roles: medical and political. He must not only make "clinical judgments" and practice "good medicine," but must also authoritatively allocate resources (Easton 1953, 130). Faced with a situation of rather oppressive scarcity, he must decide who gets what, when, and how—classic political questions (Lasswell 1936). And if relatively few persons will be affected by his decisions, the impact for these few will be difficult to exaggerate, for nothing less than life or death is involved. What makes a physician "political," then, is not merely partisan or pressure-group activity; his role as a clinician, in which he must grant and withhold resources with considerable discretion, is profoundly political, even if not ordinarily recognized as such.

Of course, this political role is nowhere explicitly acknowledged.

This is not a trivial matter, for it helps to ensure that the vast majority of patients and their families—and even a few physicians themselves—will be blind to the true nature of the situation. Thus blind, they will mistake political judgments for medical ones and be far more likely to acquiesce in the decisions. The fiction that the selection process is purely medical, in other words, is clearly functional as a powerful legitimator of rejection. It is important for its acceptance by patients and their families, that is, that the selection process not only be just but appear to be just, and this requires that it appear intelligible and patently reasonable to ordinary people (Rescher 1969, 176–86; cf. Powell 1976, 38). The ritualistic pronouncement of “clinical judgment” evidently fulfills that need, though sometimes at the cost of honesty and candor.

The unacknowledged political character of the physician’s role also forces upon him an agonizing conflict of interest. His manifest function as healer entails his primary obligation as being to his patient’s welfare; his latent function as resource allocator entails his primary obligation as being to the DHSS (cf. Merton 1949, 21–81). Though it implicitly recognizes the problem, DHSS policy is more platitude than solution:

Hospital consultants have clinical autonomy and are fully responsible for the treatment they prescribe for their patients. They are required to act within the broad limits of acceptable medical practice and within policy for the use of resources, but they are not held accountable to NHS Authorities for their clinical judgments (Committee of Inquiry into Normansfield Hospital 1978, 424–25).

But what if the physician’s clinical judgment, for which he cannot be “held accountable,” conflicts with “policy for the use of resources,” within which he is “required to act”? What, in other words, if his manifest and latent functions are incompatible? In cases of severe scarcity (as in ESRD), both functions can be made to appear to be honored only through serious misrepresentation. Of course, it is much easier to deceive patients than bureaucrats. As one nephrologist, A.J. Wing, told the *Times*:

Some of us have to tell lies to older patients, partly to make the patients more comfortable and partly to make ourselves more comfortable. We have to say to them that their hearts are too dodgy to stand the strain of dialysis (Ferriman 1980).

To the other burdens of the physician, then, must sometimes be added the demeaning necessity of lying (cf. Calabresi and Bobbitt 1978, 24–26).

Not only the *individual* patient and his *particular* physician suffer from this conflict of interest. There is a larger *societal* interest in protecting the integrity of the doctor-patient relationship, an interest enshrined in such devices as the physician's freedom from coercion to testify about his patient's medical affairs in a court of law. That relationship depends upon trust, and trust, in turn, depends upon the physician's not being seen as serving any master before the patient, an appearance evidently maintained only through occasional resort to subterfuge and manipulation.

The refusal openly to acknowledge the physician's political role has also meant that the decision-making process has escaped serious outside scrutiny, for allocative decisions have been treated as if they were conventional medical decisions. Thus, the kinds of questions regarding dialysis and transplantation that were raised in the United States in the 1960s have never been explicitly and publicly addressed by U.K. political or bureaucratic leaders; instead they have been left implicitly to the private decisions of physicians.

Consider some of the questions that have been ignored. Who selects the selectors? Shall they operate singly, in ad hoc groups, or in a more institutionalized structure? What are their qualifications to be (medical competence, of course, but what of societal representativeness or philosophical expertise)? Should the social worth of competing patients be weighed and, if so, how (past performance? future potential? personal decency? responsibility for dependents)? Is the selection process so strewn with imponderables that the only sensible course is to throw up one's hands and call for a lottery, which at least would respect the value of equality (Gorovitz 1966, 7; Childress 1979, 138; Siemsen 1978, 88)? So completely have U.K. physicians monopolized the microallocative decision-making process that virtually everyone concerned has taken the monopoly for granted, accepted it as a "given," and never seriously considered the merits of different systems.

This is not to argue that the U.K. adopt an earlier American practice, in which hospitals often relied upon selection committees composed of laymen and physicians, who were given no guidelines and developed no fixed criteria themselves (Murray et al. 1962, 315; Fox and Swazey 1974). The result, it is generally conceded, was not really satisfactory (see, e.g., Sanders and Dukeminier 1968, 377–78),

despite the unquestionably earnest, good intentions of those who took part.

Nor is it to argue for the institutionalized presence of other interests. Their representatives, lacking the authority bases of physicians, would likely be dominated by them and rendered ineffective. And if not ineffective, they might be naive or wrong-headed and greatly complicate an already nearly impossibly complex situation. Almost certainly, in any case, these interests would tend to press for treatment, for who else but representatives of patient, nurse, social worker, or other caring groups would feel intensely enough about the matter to get involved and seek a position of influence?

But it is to argue that the decision-making process often seems to exhibit a formless, almost casual character that hardly appears in keeping with its life or death significance. Greater structure, it is true, might prove a little less convenient and a little more costly than current practices. Yet it is hard to see why a refusal to treat should not require at least one nephrologist's opinion. In the United States, it is generally accepted (and for some purposes required) that a patient obtain a second medical opinion before undergoing some surgical procedures; it may not be presumptuous to suggest the need of a second opinion in the U.K. before an ESRD patient is denied treatment.

Should the patient himself participate in the discussion? Certainly, it is difficult to imagine any discussion a patient would find more stressful. Desperate, arguing for his life, not knowing exactly what information may be of help and, therefore, feeling compelled to bare his soul and plead for pity, the patient may find himself denuded of privacy and self-respect. Even if his efforts succeed, he may retain scars from the confrontation; if he fails, his bitterness may well blight much of his remaining time.

Nor is it even clear that the decision itself would necessarily be improved by his presence, for in place of medical expertise his main contribution might well be an issue-clouding emotionalism. The discomfort all this might generate for physicians, moreover, might be hard to exaggerate. Indeed, in order to avoid such agonizing confrontations, some physicians might even decide to treat patients where medical indications would seem to suggest the reverse (cf. Schwartz and Aaron 1984, 56).

At the same time, however, it *is* the patient's life that is on the line, and though many patients may prefer passively to distance themselves from the decision making, others might desire an opportunity

actively to defend their own interests. Accused criminals have such a right, of course, and while it may be objected that the doctor-patient relationship ought not to be made into an adversarial proceeding, the fact remains that a physician's decision may so profoundly conflict with a patient's wishes that it is disingenuous to speak as if doctor and patient must perforce be on the same side. There is a place for paternalism in medicine, of course, but in a democracy premised upon the individual's pursuit of his own interests, a heavy burden must fall to those claiming to represent another's interests so fully that he himself can be banished from the proceedings that may determine his life or death.

And it is to argue, too, that there is a fundamental lack of congruence between the physician's medical role, which is built on clinical autonomy, and his political role as an allocator, which implies effective accountability. As a medical actor, in the words of a former DHSS chief medical officer, "each consultant is the monitor of his own work and that of his junior" and, indeed, need not even "submit it to collective review, which is therefore poorly developed" (Godber 1982, 371). As a result, the "final arbiter of a doctor's conduct is his conscience, influenced in turn by his personal ethical code" (Warren 1979, 25).

Such heavy reliance upon internal restraints may suffice for medical actors. Indeed, all the physicians interviewed stressed that individual variations among patients made individual clinical judgment by the doctor in charge indispensable. The alternative, as they all pointed out, was clinical judgment by some physician-bureaucrat, who never examined the patient and whose rules would inescapably be so rigid as to be unworkable.

Yet physicians are political actors, too, and in democracies we normally expect the added presence of institutionalized external restraints when political actors are involved. No mechanisms—no formal statements on treating young children, persons over age 45, diabetics, those unable to speak English or of low intelligence, or other controversial patient populations—in fact, virtually no explicit policy statements whatever have been forthcoming either from the DHSS or from the Regional Health Authorities. But as these difficult, often personally wrenching decisions are remanded to the physicians on the line, effective accountability is sacrificed.

Of course, resolving such problems through criteria that determine which ESRD patients shall be treated, and procedures that govern how this determination shall be reached, would involve tradeoffs. The

doctor-patient relationship would become more formal and legalistic; physician morale and perhaps patient confidence would suffer; the responsiveness of regions and districts to local interests would be compromised; most obviously, the criteria and procedures devised (particularly, at first) would not fit all circumstances satisfactorily. Nor would the implementation of criteria and procedures cause the awkward and painful necessity of saying "no" to some patients to disappear. Indeed, rejecting patients would only become more difficult for all concerned.

And yet the current system—or nonsystem—has costs, too, though they are not always noted. The lack of accountability. The conflicts of interest. The white and not so white lies. The pretense that ethical issues can be ignored, as if the exclusive rhetorical reliance upon medical criteria were not itself an unexamined ethical judgment. The unrestrained power over life and death, especially in the hands of general practitioners and internists with only modest ESRD expertise and experience. The inequity of similar patients granted treatment here but denied there. To all this, it hardly seems sufficient for bureaucrats to observe that patient selection is left to the physicians and for physicians to reply that resource allocation is left to the bureaucrats.

Obviously, this is not the place to prescribe microallocative criteria and procedures. The issues, of course, are complex, and both the incrementalists and the expansionists can point to major strengths of their own and major weaknesses in the opposition. Moreover, however the issues are resolved, they will be resolved in the unique British context and thus cannot depart too sharply from the congeries of values, tradition, and practices that characterize that context. It may, therefore, be reckless to predict precisely what such criteria and procedures might emerge. But given the widespread dissatisfaction with micro-allocation among those with the greatest expertise and experience, it would be more reckless still to pretend that no such examination is necessary.

Conclusions

It is possible to view the ESRD microallocative process as a natural consequence of the tradition of clinical autonomy interacting with the multitudinous variations among physicians. That is, physicians are

granted vast discretionary authority to determine which patients to treat, and different physicians produce different treatment patterns, depending upon training, biases, interests, and a number of other medical and nonmedical factors (cf. Wennberg, Barnes, and Zubkoff 1982). Underlying this is the recognition that many key physician decisions are not compelled by an indisputable logic, but instead are choices presented by analogical reasoning on which experts may differ. Viewed from this perspective, disparities in treatment patterns are likely to persist so long as physicians retain their autonomy and distinctive individuality—in short, certainly for the foreseeable future.

In another sense, though, the ESRD microallocative process reflects larger macroallocative pressures. For the scarcity of resources allocated to ESRD patients is not irremediable (like, say, the scarcity of Rembrandt portraits), but rather is a function of an implicit policy decision against reallocating resources in sufficient quantities to relieve it. Put differently, the scarcity is not so much imposed on society as imposed by society, or at least by its agents. Clearly, if enough resources were made available (perhaps, less than £10 per taxpayer per year) virtually all patients would be treated. With the necessity of denying treatment effectively eliminated, the significance of clinical autonomy and physician variation as determinators of patient selection would effectively be eliminated, too.

Seen from this vantage, the U.K. experience with ESRD is simply that of a welfare state endeavoring to live within its means. In the larger view and measured in terms of direct costs, the U.K. has been remarkably successful; it devotes a smaller percentage of its gross national product to health care, and operates under a lower rate of health care cost inflation, than does almost any other industrialized nation. At the same time, though, its ESRD treatment patterns remind all other Western democracies caught up in the quest for cost-containment and cutbacks in entitlements that this involves sacrifices not only from prosperous physicians and inefficient hospitals, but also from vulnerable patients.

Yet, to acknowledge that the U.K. must live within its means is not to concede the justice of every decision made in this name, even the most carefully considered and well-intentioned of decisions. For like a sore that will not heal, the question just will not go away: in order for the U.K. to live within its means, must so many ESRD patients be abandoned to die? The obvious answer is no; so trifling

a burden could hardly be thought to exceed the U.K.'s capacity nor to be excessive, given the vastly incommensurate benefit of prolonging useful life for thousands of persons.

A less obvious answer, however, must also intrude. For if ESRD is seen as an exemplar of a larger problem—must living within its means compel a society to consign some treatable patients to death?—the response is not quite so plain. There are never enough resources to treat or aggressively to seek the cure for every malady; there are always more potentially beneficial claims (and claimants) than can be met at any level of health care funding. Moreover, individuals and governments will always conclude that as important as health is, there are other goals (sometimes, unhealthy goals) on which they also desire to expend resources. Health care, as a consequence, is not invariably the first claimant on resources, but must compete with thousands of other mundane, heroic, dangerous, or trivial goods and services in the public and private sectors. For good health may be perceived as necessary, but it is certainly not perceived as sufficient. There are many other things we also demand, and so good health is seen not as an end, but rather as a means, or a precondition, to their enjoyment. Barring the imposition of a rigid ranking placing health care first, therefore, the answer would seem to be: Perhaps ESRD patients need not be left to perish, but some sizable number of treatable patients afflicted with other diseases probably will be ignored. It is easy to deplore this conclusion and to argue for a health-dominated priority system, of course, but a free people, mostly healthy and given to focusing upon the near term, has never supported such a system. Nor does it seem likely to change its mind.

That many treatable patients will continue to perish is a very sobering conclusion. For some observers, however, a pair of other considerations may somewhat mitigate its impact. First, the problem of scarcity appears inherent in the human condition. There have never been enough resources to go around, and even as resources increase, so, too, do demands. The founders of the NHS may have believed that once the pent-up demand for health care had been met public demand would recede, but with hindsight their naiveté is exposed. From this perspective, what is noteworthy is not how many treatable ESRD patients perish but how many are saved—more today than ever before and doubtlessly even more tomorrow than today. Scarcity remains, to be sure, but major progress has been made.

Second, health care is not the only (or even the chief) determinant of health. Public funds spent on sanitation, pollution control, and police and fire protection, and private funds spent on food, clothing, exercise, and auto repair may all compete with health care for their share of the resource pie. Yet since each of these other claimants may promote good health, though they may divert resources from health care, this diversion need not lower actual levels of health. Indeed, as one analyst sarcastically phrased it, "If health status is primarily determined by socioeconomic conditions, why bother to spend money on health care in the first place instead of devoting it to improved housing, nutrition, and so on?" (Klein 1984, 90).

In the last analysis, though, such reassurances may seem to some observers too facile to persuade. For they cannot erase the image of a treatable ESRD patient drifting inexorably toward death or cancel the indelible realization that there, but for the grace of God, go us all.

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