RENAL DIALYSIS DECISIONMAKING

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The history of dialysis therapy for kidney failure and the evolution of kidney transplantation have been described by other authors (R. Rettig, Drukker, Parsons and Maher). This analysis focuses on one of the more difficult aspects of the use of artificial life-support systems: the decision to discontinue therapy. The data presented is from the University of Rochester Medical Center for the calendar years 1983 and 1984. The analysis includes all patients treated during these two years.

A formal regional program for the treatment of end stage renal disease (ESRD) patients was established in 1967 in the Rochester metropolitan area. This region has a population of approximately 1.2 million people, is comprised of nine counties including Monroe (Rochester) and extends south to the Pennsylvania border. This area is representative of the composition of the population of the United States in that there is a major urban population, relatively affluent suburban communities, rural and wilderness areas. Reports on the incidence of ESRD patients and projections have been published previously by this author (Freeman, 1975) and colleagues (Cestero, Jacobs, Freeman, 1980).
Decisions to initiate treatment with dialysis are made by review committees in each of six institutions that provide dialysis treatments. The nine county program is coordinated through a larger Dialysis and Transplant Committee established in 1967. This group* meets weekly or bimonthly to review candidates for transplantation, update treatment protocols and establish general policies. Administrative, procedural ethical and social issues are discussed in an open forum. In the early years, the group dealt more with medical acceptability for treatment of individual cases. Since the mid 1970s, the group's attention has turned toward formal policy protocols and the review of cases in which questions of discontinuation of dialysis therapy are raised. A subcommittee studied ethical problems inherent in consideration for termination of treatment for more than a year, 1975 to 1976. The general outcome of the subcommittee's report emphasized the patients freedom of choice. Legal counsel had major input into the subcommittee report and has been sought by the entire group on a continuing basis.

*Disciplines represented on the Dialysis and Transplant Committee include the nephrologist director of each dialysis unit and the director of the medical and surgical transplant programs, the organ preservation team, urology, psychiatry, nursing, tissue typing laboratory, social service, dietary, hospital administration and the clergy. Meetings are open to any responsible medical professional and patients.
To summarize the general policies of acceptance of patients for treatment, every individual who presents with kidney failure receives the right to treatment and to choose the type of treatment they desire. No patient is denied therapy. The individual hospital committees and the interdisciplinary committee may conclude that dialysis treatment may not be in the best interest of a patient as it may result in a prolongation of the dying process. However, if the patient chooses not to accept the recommendation of the committee and is competent, the patient is accepted and every available resource is utilized for treatment without prejudice.

All modalities of therapy are offered and, henceforth, for purposes of this report, they will be referred to simply as dialysis or transplantation. There has never been a discussion or a judgment about the "social worth" of a patient.

All patients under consideration for a renal transplant undergo a lengthy evaluation and are screened for medical, surgical, urologic, social problems and anesthesia risks under a defined protocol. The key members of the Dialysis and Transplant Committee that evaluate potential transplant recipients are a nephrologist, a vascular transplant surgeon, a urologic surgeon, a psychiatrist and a social worker.

The principles of access to therapy and freedom of choice in our community are consonant with the judgments of the Supreme Court that established the penumbra of the right to privacy and self-determination under Common and Constitutional Law (Rowe vs Wade); the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter
known as the President's Commission) and the opinions of most ethicists that support equal access to care and freedom of choice.

Decisions to discontinue treatment are not so straightforward. The objective of the patient care team is to address those difficult problems in the context of medical data and social, legal and ethical tenants. No single physician or medical professional can render this decision. There must be common agreement between three qualified physicians and the patient, if competent, or the legal next of kin in patients who are not competent.

DEFINITION OF TERMS

Loss of function of the kidneys to a level that is incompatible with life will be referred to as renal failure. Medical textbooks separate renal failure into two categories: acute renal failure and chronic renal failure.

Acute renal failure is defined as sudden loss of function caused by several hundred diseases, toxins, changes in blood circulation and obstruction to urine flow. Many of these patients may regain natural function of the kidney if they can be supported by the artificial kidney and close medical management. Others die from the underlying disorder that caused kidney failure. Some never regain function but can be maintained by the artificial kidney for an indefinite period. These patients are desperately ill in the early phases of loss of function because the underlying insult to the kidney also affects other organ systems.

Chronic renal failure is irreversible loss of kidney function from a large
variety of known and unknown causes. Natural kidney function will not return in these cases. These patients have end stage renal disease (ESRD) and decisions to initiate therapy are made before the patient is in danger of dying. These patients are eligible for Medicare benefits after dialysis treatments have started or when they receive a transplant. Discontinuation of treatment of patients on long-term dialysis in this category was analyzed by Neu and Kjellstrand (NEJM 1986; 314:14-19). This is a valuable publication but does not address decisionmaking in patients with acute renal failure.

These textbook definitions are useful only after a diagnosis of the basic disorder has been made. Decisionmaking would be more rational and efficient if the cause of kidney failure were known before dialysis therapy must be initiated. In the real world, individual patients often present with life threatening consequences of kidney failure (uremia), and emergency dialysis treatments must be started before a definite diagnosis is established.

For this reason, new patients have been divided into two groups according to the manner in which they present for diagnosis and treatment: those with sudden renal failure and those with known chronic irreversible renal failure.

Sudden renal failure indicates the urgency and primacy for treatment before a diagnosis of the underlying cause is made. Sudden renal failure is further divided into those cases that follow major surgical procedures and those due to medical conditions to determine outcome and costs. Most studies about decisionmaking focus on patients with chronic irreversible disease (ESRD). This analysis is meant to be comprehensive and includes those patients who are first seen in an emergency situation and require dialysis treatment
before a definitive diagnosis is established. The importance of including these patients is: 1) There is the possibility of recovery of natural kidney function; and, 2) It is the group in whom the largest percentage of patients eventually have a decision made to discontinue treatment.

All of the 228 patients are divided into the following six groups:

1) Sudden renal failure following surgery for catastrophic vascular accidents, complex major procedures on the heart that utilize cardio-pulmonary bypass, and operations on two or more major organ systems.

2) Kidney failure that occurred suddenly or was not previously known to exist. These are emergency cases that require immediate treatment because they are in danger of dying from retained toxins, fluid overload or chemical imbalance.

3) New patients with known kidney disorders that progressed to end stage renal disease in 1983-84. These patients were known to have irreversible chronic renal disease, progressive in nature, and were started on dialysis therapy in 1983 or 1984.

4) Patients on maintenance dialysis treatment transferred from other facilities because of complications, inter-current illnesses or incidental surgical procedures. These patients were on dialysis for months to years prior to the admission for intercurrent problems.

5) Patients who received a kidney transplant before the two year study
period, had adequate natural function of the transplant, but had progressive chronic rejection or recurrence of their original disease. These patients returned to maintenance dialysis treatments in 1983-84 to wait for another transplant or to remain on dialysis depending on their preference and their medical condition.

6) Patients who received a new kidney transplant during the two year study period.

ANALYSIS OF PATIENT DATA

Data on all patients who received dialysis therapy or who had a renal transplant, during the calendar years 1983 and 1984, were retrieved from the University of Rochester Computer Center by an IBM 4381 Computer in an MVS environment using SAS software. The information used in this analysis is listed in Table I and co-morbid conditions in Table II. The diagnoses, hospital course and discussions of decisions were crosschecked by review of written records of weekly care rounds, minutes of the interdisciplinary Dialysis and Transplant Committee, operating room records, formal patient hospital records and other sources. Fiscal data are true charges, not costs. Diagnosis Related Group (DRG) classification is the principal diagnosis at discharge, not admission.

RESULTS

Two hundred and forty-four patients had 562 admissions for dialysis or transplant in the two year study period. Complete data is not available in 10
patients, 6 patients had 10 admissions for drug overdoses, received treatment by hemoperfusion and are excluded from this analysis. The final population consists of 228 patients who had 537 admissions.

The characteristics of patient groups are summarized in Table III. No statistical analysis of differences between groups is presented because this study is not prospective, no control groups were utilized for age, sex, race, co-morbid conditions or other variables. The true base population characteristics for co-morbid events and hospitalization data are beyond the scope of a study of this type. Further, the groups are not comparable because the purpose of the study is decisionmaking in individual patients who present in a unique manner. Finally, therapy was rendered with different goals for each patient group and, therefore, the groups are not strictly comparable.

A number of known observations are confirmed by the data in Table III. First, the incidence of renal failure in blacks is very high.* Second, the number of diabetics in the irreversible renal failure groups accounts for approximately 1/3 of the total patients. This is in contrast to patients that present with "sudden" renal failure where the percentage of blacks and diabetics are closer to that of the general population.

*The percentage of blacks in Monroe County (Rochester) is 10.1% and of the nine county region 6.8% or 81,264 of 1.2 million. (Data from the 1980 census supplied by the Center for Government Research, Inc.).
Other findings are not surprising. The proponderence of males in the post-surgical "sudden" renal failure group reflects the higher incidence of vascular disease of the coronary arteries and the large vessels that lead to catastrophic events (myocardial infarction, ruptured abdominal aortic aneurysms, bypass procedures, vascular grafts, etc.). More females on maintenance hemodialysis were transferred in for intercurrent illnesses compared to the number of males. Seven of the 19 females required surgery for metabolic bone disease. This is a common complication in patients on long-term dialysis therapy, but more severe in females.

Younger patients received transplants because vascular disease in the elderly exclude consideration for transplantation. The number of co-morbid conditions is less in the transplants but there is a high percentage that are diabetic.

The large diabetic population in the established chronic renal failure and transplant groups may give a false impression that more younger patients receive dialysis and transplant treatments. Early onset diabetes (juvenile diabetes) occurs early in life and complications occur in midlife. Renal failure is the major life threatening complication in 50% of these patients. Thus, the incidence of diabetes moves the age scale toward younger persons, e.g. those below age 65.

The number of co-morbid conditions is roughly the same in each group except the new transplants. This data is probably of little value except to demonstrate that virtually all patients have one or more disorders other than renal failure. In fact, only 4 of the 228 patients were free of major
complications of renal failure and diseases of other organs. It is the type and severity of the co-morbid condition that determines the outcome, not the number. For example, severe coronary artery disease is more serious than anemia or low back pain.

Because the process of decision-making is the subject of this report, one observation from Table III is emphasized. Forty-two percent (95 of 228) patients were not known to have renal disease by the medical staff or the referring physician when they first appeared for diagnosis and treatment. These patients with "sudden" renal failure were critically ill and in danger of dying from chemical imbalance, fluid overload, or retained lethal toxins at the time of presentation. In these individuals, the primary diagnosis becomes a secondary consideration and the immediate directive is to restore the chemical and fluid status of the patient to less dangerous levels by initiation of dialysis. After one or more treatments, definitive studies are conducted to determine the cause of renal failure and whether or not there is the potential for recovery of natural kidney function.

If the new transplants are excluded from the total group, then 53% of all patients fall into the "sudden" renal failure group. If only patients started on dialysis therapy for the first time are considered, those with an uncertain outcome represent 69% (95 of 137) of all new patients treated at Strong Memorial Hospital (SMH).

This institution is the Hospital of the University of Rochester Medical Center and the major Tertiary Care Center in this area. It is possible that the percentage of new cases that are "sudden" or acute renal failure is higher
than might be representative for the region.

The exact number of new ESRD cases started on dialysis in the nine county area in 1983-84 was 200.* Twelve of these came from the "sudden" renal failure group and 42 from the new chronic renal failure group started on treatment at SMH. The remaining 83 cases of sudden renal failure regained natural function or died (Table IV).

Not all "sudden" or acute renal failure cases occur or are referred to SMH so the figure of 83 cases with the potential to recover function, who will die of their basic disease or in whom a decision must be made to discontinue therapy is a minimum number. The conclusion is that at least 30% of all new patients started on dialysis therapy may not have had a diagnosis established and the outcome is unknown at the outset.

Data on patient outcome (Table IV) confirms this point. A decision to withdraw treatment was agreed upon in 24% of the patients who presented with "sudden" renal failure (23 of 95), the largest portion in any of the patient categories. However, just under 30% of patients with "sudden" renal failure had return of natural function and were eventually discharged from the hospital without the need for support with the artificial kidney. Thirty-four percent died and 13% remained on chronic dialysis.

*There were 110 new ESRD cases started on dialysis in 1983 and 90 in 1984. The incidence is 92 and 75 cases per million population. The 1985 incidence was just over 100 cases per million.
Table IV is a summary of the outcome of the six groups. Tables V through IX summarize subgroups according to age, sex, length of hospital stay for the procedure or occurrence of kidney failure or transplant, additional admissions and hospital charges. Table X compares mean hospital charges per patient for each of the subgroups and Table XI is a computer printout of the DRG classification of the patient admission analyzed in this study.

Transplant candidates are encouraged to continue on dialysis if they have significant vascular, pulmonary or other disorders that may jeopardize their life because of the side effects of continuous immunosuppressive therapy. They are not excluded, however, if there is a reasonable chance of success. The higher risk is supported by the characteristics of the three deaths in the transplant group: all were diabetic and over 50 years of age.

Excluding the transplants, 69% of the patients were over 50 years of age and 35% were over 65. Other findings are evident from the tables. Length of stay and hospital charges were highest for those with the most serious illnesses: those with "sudden" renal failure following surgical and medical procedures. A deliberate decision to discontinue treatment made no difference in the length of stay or hospital charges when the patients are compared as groups. All data is available from the tables or can be calculated from the information provided.

In group 3, known patients with irreversible disease, three died and two discontinued treatment. The 12% mortality rate is consonant with national figures and significantly lower than the "sudden" renal failure group. The three deaths on dialysis were due to non-renal complications that occurred
after therapy was initiated. In two, therapy was withdrawn by common agreement 43 and 57 days after the first dialysis. From the beginning of therapy, there was an understanding of the expectations by the patient.

The first patient, with irreversible disease in whom treatment was discontinued, was a 67-year-old female with severe hypertension and coronary artery disease. There was an understanding at the beginning that there would be a 4 week trial of therapy and treatment would be discontinued if, in her view, she failed to have significant improvement of her angina and congestive heart failure. Unfortunately, there was no improvement and treatment was discontinued. The other patient, a 70-year-old woman, had obstruction of urine flow from a pelvic cancer. She was advised that chemotherapy was unlikely to cause regression of the tumor though her kidneys had been irreparably damaged. When the tumor failed to respond to treatment, she requested that dialysis therapy be discontinued. She was judged to be mentally competent and her request was granted. Data on the other patient groups is contained in the tables.

DECISIONS TO BEGIN DIALYSIS

As stated, all persons who are in danger of dying because of the consequences of kidney failure of unknown cause received dialysis as discussed above.

There are individuals with known progressive disease who chose not to have dialysis or are never referred for treatment. This is not uncommon but the exact number is unknown.
DECISIONMAKING

Thoughtful people are likely to agree that the multitude of variables crucial to decisionmaking for patient care cannot be captured by a cool analysis of statistics of patient outcomes, costs, co-morbid conditions, fear of litigation and societal pressures. The drama of each individual life cycle is a dynamic course of known and unknown variations in the essence of being. The ebb and surge of courage and fear, satisfaction and contempt, arrogance and humility occur in everyone. These conscious emotions are not reflected in the tables. The nature of humans is singular.

A man of sound mind, 77 years old, has known for many years that his kidney disease is progressing toward death from accumulation of toxins. His trust in two physicians and the maze of the medical care system caused him to follow a program of conservative measures that restricted his freedom to enjoy retirement. Conservative treatment has prolonged his life for a year or more free of artificial life-support systems. Gradually, however, over the last year, he has begun to recite the early symptoms of kidney failure. His tolerance for exercise is decreased and his ability to concentrate for prolonged periods of time has deteriorated.

He knows about artificial devices that might prolong his life. His wife and he have discussed whether or not he should have a trial of therapy. But he has accepted the natural course of his affliction and sits side by side with his beloved companion of 50 or more years and states that he does not wish to have treatment.
He appears content, but at times anxious. What will be the symptom that heralds his demise? He calls on occasion to inquire whether this or that is the beginning of the end. Most of these symptoms are trivial but to the patient they do not seem so trivial until reassured. He is not an eccentric nor is he psychologically disturbed in any way. His kindly and soft demeanor is accepting.

When told that the end will be soon, perhaps within months, the couple trust and wait. They grow closer.

He has exercised his freedom of choice.

Mr. WK is a 49-year-old diabetic with progressive renal failure. He is legally blind from diabetic retinopathy and can make out shadows only. He has severe degenerative disease of his peripheral nerves so that he has very little pain or pressure sensation in his lower extremities. Because of the loss of sensation, a chronic pressure ulcer developed on the heel of his left foot. The likelihood of healing this ulcer is marginal because of the poor circulation to both feet. He has had one myocardial infarction. His appearance is that of a man 20 years older than his true chronologic age.

He was admitted to the Intensive Care Unit because of diabetic ketoacidosis in coma. His blood sugar was controlled with repeated doses of insulin and his fluid balance was gradually restored to normal. About 10 days after his coma cleared, he was informed that his kidney function was 15% of normal and progression of his disease was almost
The patient, his wife and two sons were told the details of dialysis treatment. A fistula would have to be created; treatment would be four hours three times a week; wide variations in his blood sugar were likely; leg cramps and generalized fatigue would probably follow each treatment. The patient's wife and the sons toured the Dialysis Unit and the details of each procedure were explained to them. The same details were also described to the patient. The opinion of three physicians was that he was not a candidate for transplantation because vascular disease would not allow connection of blood vessels from a donor kidney to his own arteriosclerotic vessels.

Mr. K never waivered from his determination to live as many years or months as possible. His answer to the suggestion that treatment may prolong his pain, that amputation may be necessary if his foot ulcer became infected, that he may have another heart attack or other vascular occlusions has been the same: "Doctor, if I can have a few extra months or years with my wife and sons and enjoy the sound of my grandchildren at play, I want dialysis".

His stately wife assures us that she will provide her husband with every detail of care. Each of his sons insist they will alternate the responsibility to bring him to a center for dialysis. The patient and each member of his family have been told again and again that dialysis will not cure or even improve his vascular
disease. But at the conclusion of each discussion, the family is certain to thank every member of the health care team and to remind us in a quiet and respected manner that Mr. K wants to live and they will be most grateful if we will extend to him treatment for his kidney failure.

Mr. K will be started as his fistula has been created and is ready for use. What cannot be described adequately is the acceptance, trust, courage, love and gratitude of the patient and his family.

In 1975, the Chairman of the Dialysis and Transplant Committee (the author) raised two issues for consideration of the Committee:

1. Given the theoretic possibility that facilities for dialysis treatments may be inadequate for all ESRD patients, how would the community cope with the situation in terms of selection of patients for treatment?

2. What should be the proper and accepted process to discontinue treatment in those patients already started on dialysis therapy who sustained complications that rendered them infirm, dissatisfied or incompetent mentally?

A Subcommittee was appointed to discuss these issues and other issues. The Chairman was the Cannon Reverend Nathanael Whitcomb, a distinguished scholar of the Episcol Church and Protestant Chaplain to Strong Memorial Hospital. The group also included Dr. William A. Greene, distinguished Professor of Medicine and Psychiatry, member of the Medicine-Psychiatry Liaison Group and of the original Gottschalk Committee that was convened by the Bureau of the Budget
in 1967 to consider the phenomena of prolonged life-support with the artificial kidney. Other members of the committee included the Catholic Chaplain to the hospital, a practicing nephrologist, a transplant surgeon, an anesthesiologist, a nurse, and a social worker.

The Subcommittee addressed a "coping" process, which actually was a prospecting method of determining how well patients fared on dialysis treatment. The acceptance of patients into the Dialysis and Transplant Program has never been a problem. As stated previously, all patients receive therapy under free choice unless the individual refuses dialysis and is judged to be competent and rational, or has made a clear statement when competent that they do not wish to have therapy if the "need" arises and they are not competent. The committee's draft report contains a discussion on the discontinuation of treatment including recommendations from legal counsel. The full draft report is attached in the Appendix.

The Subcommittee identified clearly the difference in consideration of beginning therapy and the legal and moral responsibilities of medical professionals after treatment had been started. The deliberation of the Subcommittee emphasized what is "standard of care in the community", the gravity of the need for medical professionals to offer all available help and to honor "the rational convictions of the right to control ones life with the concomitant right to exercise that decision".

At that time (1976), there were few legal or moral guidelines regarding discussions to discontinue treatment.
In the ensuing 10 years, the approach has evolved into a verbal contract between medical professionals and patients, if competent, or the legal next of kin in incompetent patients. This approach has been useful, particularly in patients with "sudden" renal failure, when the exact diagnosis and the possibility for recovery of natural renal function are not known at the time of presentation. It is also of value in those chronic patients on dialysis treatments who sustain complications such as cerebral vascular accidents, progressive heart disease, or developed neoplasms after they have been on dialysis treatments for months or years.

An agreement on a trial period of intensive treatment allows the medical professionals time to establish as exact a diagnosis as possible and to adjust therapy to an optimal level to allow maximal rehabilitation. The trial period also allows the patient and the family time to come to grips with the gravity of a decision to discontinue treatment.

The following are two examples of extremes encountered in this approach.

A 69-year-old widowed female was started on maintenance hemodialysis in a hospital in a distant city 6 months before transfer to Strong Memorial Hospital. She had a history of hypertension, adult onset diabetes, and had had several myocardial infarctions. She had angina at rest on admission.

She moved to Rochester to live with her married daughter and to receive consultations from cardiologists and nephrologists.
Initially, the patient was restricted to bed by the limitations of her heart disease as she became short of breath and developed chest pain on the least exertion. After diagnostic studies, her dialysis treatments were altered to adjust fluid volume to minimize fluid overload of the heart and other adjustments were made in her medications to improve cardiac function. During the first week, the cardiologist, nephrologist, dialysis nurses, social workers, and others discussed her personal, medical, and social situations with the patient, the daughter and son-in-law.

When it was evident to all that the likelihood of improvement was nil, the concept of a trial of maximum therapy for a finite period was raised first with the daughter, the son-in-law, and then with the patient.

These interactions are delicate and sensitive. They are initiated on an individual basis depending on the presentation of the patient and their situation. In this case, the approach to the patient began: "Mrs. ____, it is difficult to come into a person's life for only a small fraction of your 69 years and begin a conversation about your very serious condition ......". The patient accepted the concept of a trial of intensive therapy with the understanding that a complete re-evaluation of her entire status would be made at the end of four weeks of intensive treatment. Nothing more was said for four weeks regarding the re-evaluation, except to answer the questions of the patient and the family and to explain why certain adjustments in the treatment program were made.

At the end of a full month, the patient was still unable to move out of
bed without severe chest pain and shortness of breath. The daughter's home situation had been judged to be excellent, the son-in-law had expressed his support of his wife to care for his mother-in-law in separate private conversations. Then, privately, the two volunteered jointly that the patient would be accepted with loving care into their home.

Subsequently, the patient was informed that there was little hope for improvement in her condition by a single physician. Later in the conversation, as planned, the patient and the physician were joined by the daughter-in-law and husband. This was done to assure the patient that the daughter and son-in-law understood her problem and wanted her to come home with them. Eventually, the woman decided that she would be more comfortable in her daughter's home for her last few weeks. The emotions of this discussion were intense and when it was over, there were tears on everyone's cheeks.

She died 19 days after discharge in the daughter's home.

At the other end of the spectrum, sharing and trust are not easily accomplished.

A widowed female, age 66, had been on maintenance dialysis for 8 years. In 1978, she suffered a cerebral vascular accident with left hemiparesis. In 1983, she sustained a right-sided paralysis leaving the woman unable to communicate or to perform the most simple task.
Her heart was unstable requiring monitors and other resources available only on the Medical Intensive Care Unit.

The nephrologist who had referred the patient to Strong Memorial Hospital after the second vascular accident, had tried to bring the four sons together to discuss further treatment and had contacted legal and state authorities regarding the possibility of discontinuing treatment without consent of the four sons. These efforts were continued after the second cerebral vascular accident when the patient was admitted to Strong Memorial Hospital. Three of the sons remained adamant that every possible treatment should be continued for their mother.

The medical professionals had all agreed that the outlook for recovery to a meaningful existence was hopeless.

Without consent of the legal next of kin, however, no one believed that they had the ethical or legal right to discontinue treatment. The woman remained hospitalized for a total of 69 days, mostly on the Intensive Care Unit and finally died of overwhelming sepsis. Dialysis therapy was continued to the very last day before death.

In 67 other cases in this study that died, there was a distinct different scenario for each individual case. Unlike the report of Neu and Kjellstrand, there is no identifiable decisionmaker about discontinuation of treatment unless it was the patient. Even then, there were frequent reversals of decisions once made with firm conviction. The cases listed as dialysis discontinued are largely those who were incompetent or a few who never waivered from their decision to have treatment discontinued. There are only two axioms
that apply to all of the cases in this analysis: 1) The patient was allowed freedom of choice or in the case of patients mentally incompetent, documentation that the patient would have exercised a choice to continue or discontinue therapy was required before a decision was reached by the health care team to continue or discontinue treatment. 2) In any patient where there was even the slightest hint of litigation, every possible measure to treat the patient was followed despite personal or collective convictions by the medical professionals that treatment was not appropriate.

Thus, decisionmaking has evolved from the more paternalistic and authoritarian tone of the report of the Subcommittee of 1976 to one of freedom of self-determination by the patient. And, as medical liability has become more costly and threatening, the health care team increases efforts to avoid litigation, regardless of cost, despite the recognition that cost containment is a responsibility of all concerned.

In the face of these conflicting pressures, there are many cases in which patients and families have had positive benefits that defy quantitation.

A 70-year-old executive was started on regular dialysis therapy for ESRD due to hypertensive kidney disease (nephrosclerosis) in 1978. This courageous man traveled extensively through Europe and the United States, continued to manage his business and was active socially for four and a half years. His last six months were difficult because of the progression of bone disease and heart failure. However, during the five years on dialysis treatment, he trained his son to manage the family business, earned the respect and love of his son and left his firm and its employees
in its most positive and financially secure position in its history.

A 62-year-old man had a kidney removed in 1977 because of a malignant tumor limited to that single kidney. It is not uncommon that this type of tumor recurs in the other kidney, and a second tumor appeared in the remaining kidney in 1983. This kidney was resected successfully with the patient on dialysis therapy, and he remains in relatively good health to this date.

A 13-year-old male was known to have nephritis for two years which caused massive loss of protein in his urine and modest loss of kidney function. He was transferred to the Pediatric Intensive Care Unit with massive fluid retention that restricted his ability to breathe, decreased his cardiac output and caused rents in the skin of his extremities and trunk with weeping fluid. Both eyes were closed because of the fluid collected in the subcutaneous tissue in his face. He was started on dialysis to remove fluid but with a full recognition that his marginal kidney function would fail completely as it almost always does when dialysis is initiated. This was a purposeful decision since the object was to prevent loss of protein in the urine which would directly improve the severe state of fluid retention. After multiple dialyses, surgical procedures to drain fluid and several episodes of infection, he was discharged after six weeks on a regular dialysis program. Six months later, he began to produce small amounts of urine that were relatively free of protein. He gradually increased his urine output eventually reaching 40% of normal function without the need for dialysis. Why he recovered function spontaneously is not known but he is well today and
leads a relatively normal life.

Although the latter case is unusual, it is by no means rare. In addition to this case, four others with known renal disease of uncertain cause had kidney failure that at times required treatment with the artificial kidney over the two year study period. In these patients, the activity of their kidney disease waxed and waned allowing periods of months off of dialysis but having to return when the function declined. These cases resemble kidney transplants that undergo episodes of rejection that may or may not be reversible with anti-rejection therapy. The difference is that the cause of these primary chronic diseases of the kidneys is unknown, and the mechanisms whereby natural function returns has not yet been identified.

Types of cases are categorized below. This organization of groups is meant to illustrate some, but not all, of the variables in decisionmaking. It is done at the risk of giving an impression that each case is not individualized.

1) Therapy is discontinued after a trial period under verbal contract with the patient, if competent, or the next of kin if the patient is mentally incompetent.

2) Patients may undergo an unexpected improvement in function such as illustrated by the last case described above.

3) Patients may have unexpected benefits that are never known to the medical care team that relate to the positive effect on the family,
employees or other friends.

4) Dialysis allows new benefits to patients such as the removal of both kidneys for tumors that usually appear only in the kidneys and eventually will metastasize.

5) Patient equivocation occurs frequently where the will to live and the desire to give up constantly change making a clear plan for re-evaluation difficult.

6) Physician equivocation occurs in some cases. Here, a referring physician may not allow the medical team to enter into a contract with a patient or may fail to allow a "do not resuscitate" order in the patient's chart.

7) Patients may not be able to come to grips with a decision regarding discontinuation of therapy or the family may equivocate as described in one case example above. In these cases, dialysis is continued indefinitely.

8) Patients may have unrealistic expectations of the results of treatment, become depressed, do not make full efforts to become rehabilitated and continue on treatment without significant improvement.

9) Patients may be unable to cope with complications, have a downhill course and die.
(10) Very difficult patients have unreasonable demands that continue to annoy the health professionals and at times disrupt optimal care. The most difficult examples are transplant recipients who discontinue their immunosuppressive drugs after years of a successful functioning transplant. They become convinced that there is no need for continuation of anti-rejection therapy. Obviously, the kidney rejects and the patient returns to dialysis.

(11) Some patients are in uncharted territory, and the outcome of the disease is unknown to professionals. We simply know too little about too many disorders.

As with any summary, there are areas that probably require expansion or where there is significant overlap.

THE REALITY OF DIALYSIS TREATMENT

Throughout this report, the concept that each individual is unique has been emphasized. Categorization of patients or of medical professionals is fraught with problems of an infinite number of variables. On the other hand, the analysis of cases as individuals without statistical scrutiny leaves any report open to valid criticisms. This report could be criticized as a series of anecdotes of a method of personalized delivery of care.

Illustrative of problems in decisionmaking by case vignettes emphasizes uncertainties of biologic events and adaptation to treatment. The traditional approach is to organize patients into groups according to the manner in which
they present and by their outcome. This results in depersonalization of a report.

In accord with the opinion of others, the value of anecdotes is very useful to supplement an organized analysis (see President's Commission, specifically, Moran's objection to the value of anecdotes, page 8; and Commissional Valentine, page 201, volume 1). Though an attempt has been made to utilize the categorization approach, it has been supplemented with anecdotal presentations to illustrate the personalization of treatment. As Cassels (NEJM 1982; 306:639-645) points out, each person has dimensions beyond values and beliefs: each person has his own personality trait and behavior pattern with which they address an illness; a person has a past, memories and skills learned, without which they are incomplete; life experiences, particularly of previous illnesses bear on their perception of medicine as a science or an art; their family is a part of their person; cultural background dictates their attitudes to a host of variables; the individual has roles important to him or her and has a particular way of relating to others. Each person is political, creative, ignorant of new changes in their environment and has certain creative behavior patterns. Each patient has a strong image of their own body and the fear of how it may be altered by illness. Each individual has fantasies that are shared with no one and has a "perceived" future in which "hope dwells". Each person has a "transcendent dimension, a life of the spirit" which may or may not be religious or mystical.

A second reality that has been emphasized in this report is the difference in discontinuing treatment in patients in whom dialysis has already been started compared to the patient not yet treated. At least two features of this
dilemma deserve comment.

First, there is the uncertainty of the outcome. There are publications pertaining to uncertainty by medical professionals and their failure to relate this uncertainty to patients (Fox, Drummond). There is only one certain fact and that is that someday we will all die. Otherwise, there are no absolutes in the responsible practice of medicine. One speaks in terms of percentages: that there is a 95% chance that a live-related donor transplant will be functioning at the end of one year or that the mortality rate of all patients started on dialysis is 15% per year. However, for the individual with a given illness, there are no guarantees and it is the foolish person who speaks in terms of no risks or no hope. Those that develop criteria to predict an outcome of 100% must be viewed with extreme caution. For example, two recent publications emphasized age as a major variable that predicts a poor outcome (Romsussen, et al: Arch Intern Med 1985; 145:2015-2018, and Lien and Chan: Arch Intern Med 1985; 145:2067-2069). There are 10 examples of contradictions to "predictive factors" of inevitable death in this report alone. Unexplained deviations from the expected outcome occur everyday in every institution in the world and countless times in the career of a busy practitioner. Presentation of percentages is of some benefit to the individual patient to assist in reaching a decision but for that person the percentage of success or failure will be 0 or 100%.

The events that have to do with the course of nature are always uncertain despite the highest level of expertise of medical professionals. The greater the lack of scientific knowledge, the more likely is the uncertainty. Finally, knowledge need not necessarily be hidden from a patient, but it may be impossible to communicate with certain individuals since we all have
imperfections of perception.

In this group of patients, there were many uncertainties particularly in the first two groups. But there is the singular assurance that virtually all would be dead, irretrievably dead, if they had not receive the life-support treatments under scrutiny here.

Thus, the tendency was strong to err to treat too many persons rather than too few. This tendency was regardless of the age of the patient or the numbers of complications except for those where procedures could not be conducted because of technical problems.

Second, there is a lack of definition of what dialysis does. Dialysis replaces the function of a vital organ system: the kidneys. Dialysis is by no means perfect in its role of replacement. It must be defined as a series of procedures that replace the function of a vital organ system. This is quite different than a respirator or pacemaker because these are devices that assist an existing organ. If the lungs fail completely, a respirator cannot replace pulmonary function. A pacemaker is useless without a viable heart. At this writing, the artificial heart is an experimental device not yet proven for routine use.

There are only two analogies that are, or were, in regular clinical use. The artificial lung was used in patients with poliomyelitis when the nerves that innervate the respiratory muscles were affected and respiration ceased. The "iron lung" replaced the function of the muscles of respiration. It has often been used as an analogy to dialysis therapy. The second is insulin
therapy in diabetes mellitus, particularly juvenile onset diabetes. The cause of diabetes is loss of function of the islets of Langerhans and the resultant lack of insulin to sustain life. As far as known in this society, it is not conscionable to withdraw insulin therapy and allow death to occur from hyperglycemia or ketoacidosis coma. Likewise, it was not customary to withdraw the artificial lung in the poliomyelitis cases.

The concern about withdrawing dialysis treatment is then clear. To emphasize the point in the extreme, the question is whether there is such a thing as a natural death from kidney failure in the era when artificial kidneys are in common use?

Is there a moral imperative here? If the answer lies in the basic right to privacy and self-determination, then the decision resides with the individual patient. If the patient is incompetent, then the decision is left to others. There is no ethical precedent here except to do what is right, a woefully ill-defined charge.

In the State of Massachusetts, the Supreme Judicial Court ruled that the matter of withdrawing dialysis therapy is a matter for the Court to decide even though the next of kin and the physician have agreed that the most reasonable course was to discontinue treatment in an individual judged to be incompetent (the matter of Earl and Springs, Mass., 405NE2d 115, 1980). This is the only Massachusetts case that addressed dialysis therapy in incompetent individuals. Other decisions in that state are consistent about life-support systems in individuals unable to make their own decisions (Sakowicz to Brophy).
If this precedent is followed, the courts will indeed have their hands full. The cases presented in this report indicate that 30 cases would have been presented to the courts in this area in 1983-84 for dialysis cases only. In the usual course of judicial events, many would not have received final judgment as of the writing of this report.

Consideration of alternatives inevitably leads to the Congress of the United States. Recommendations for action are presumptuous except to observe that responsible decisionmaking in matters that are clearly life and death situations is upon us.
REFERENCES


2. Rettig RA: Implementing the End Stage Renal Disease Program of Medicare. The Rand Corp. (C) 1980, Santa Monica, CA.


