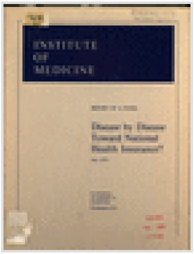

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INSTITUTE OF MEDICINE

DISEASE BY DISEASE TOWARD NATIONAL HEALTH INSURANCE?

Report of a Panel:
Implications of a Categorical Catastrophic Disease Approach to National Health Insurance

June 1973

National Academy of Sciences
Washington, D.C.

WOODROW WILSON SCHOOL
OF PUBLIC AND INTERNATIONAL AFFAIRS
PRINCETON UNIVERSITY

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and Public Affairs

PRINCETON, NEW JERSEY

May 30, 1973

Dr. John R. Hogness
President, Institute of Medicine
National Academy of Sciences
2101 Constitution Avenue
Washington, D.C. 20418

Dear John,

I am pleased to present to you and the Institute of Medicine the Report of your Panel on Implications of A Categorical Catastrophic Disease Approach to National Health Insurance. This report has the agreement of all members of the panel.

The panel wishes to acknowledge with thanks the excellent and invaluable assistance of the staff, Dr. Laurence R. Tancredi, Mr. Paul C. Rettig, and Mrs. Gloria Ruby.

Faithfully,

Herman Somers

Herman M. Somers
Chairman, Panel on Implications
of a Categorical Catastrophic
Disease Approach to National
Health Insurance

HMS:bh

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IMPLICATIONS OF A CATEGORICAL CATASTROPHIC DISEASE APPROACH TO NATIONAL HEALTH INSURANCE

The Social Security Amendments of 1972 (P.L. 92-603) contain a controversial provision that workers and their dependents with chronic renal disease who would benefit from hemodialysis or kidney transplantation would be deemed disabled for purposes of coverage under Parts A and B of Medicare. This provision is brief, stating that those patients who qualify for end-stage renal treatment will be covered by Medicare after a three-month period on hemodialysis. Unlike Medicare eligibility requirements for disability, this provision would cover nearly everyone -- Social Security beneficiaries, those insured under Social Security and dependent family members -- afflicted with end-stage renal disease. This provision becomes effective July 1, 1973, with an estimated cost of $135 million for the first year and possibly reaching a level of as much as a billion dollars in federal costs per year by the tenth year. At that time the number of patients brought into the program could equal the death rate of those on the program.

This review panel was appointed in March 1973 by the Institute of Medicine in response to the passage of the Social Security Amendments of 1972. Our charge had been broadly conceived; we were asked to prepare a policy statement on the implications of a disease-by-disease approach to national health insurance. To accomplish this, we first weighed the pros and cons of the renal provision that has been enacted and then arrived at a position on the appropriateness of this approach for coverage of patients afflicted with other serious conditions.

Proponents for passage of this provision have presented strong medical, economic, and political reasons for selecting kidney patients for special consideration at this time. First, the methods of treatment for end-stage renal disease make this particular condition exceptional. From the medical standpoint, hemodialysis and transplantation are viewed as life-extending therapies that have surprisingly good results. The patients that would benefit from such treatment, numbering 8,000 to 10,000 patients per year initially and reaching an estimated stable level of 60,000 patients by the tenth year, could return to active life and be useful citizens. It is, therefore, argued that a nation as richly endowed as ours cannot justify withholding life-extending therapy that can have such beneficial results simply because of the high cost of treatment. Along this line of reasoning is the feeling expressed by many that, although only one particular disease is selected for coverage under Medicare, it is on balance better for society to help one group of patients than none at all.

Second, partially due to the relatively small numbers of patients that would require hemodialysis or transplantation treatment, costs for such coverage, certainly for the first year of implementation of this provision, are insignificant. With a $10 billion a year budget for Medicare, $135 million for the next year to cover these patients is relatively inexpensive. The long-term cost of possibly a billion dollars a year for this treatment may be compared with annual health expenditures in this country that will undoubtedly well exceed $100 billion, although it will represent a far larger portion of the margin that is discretionary.

A third argument for this provision rests on the fact that the Social Security Amendments would otherwise have provided inadequate coverage through the disability provision for people requiring kidney dialysis. There are two reasons for this. First, patients receiving hemodialysis are often able to work and would therefore not be classified as disabled. And second, in order to qualify for this coverage an individual would have to be disabled for at least two and a half years. In a case of end-stage renal disease, the patient, left untreated, would suffer an early death, and thus this requirement would have precluded his ever qualifying for assistance.

In addition to these three arguments for inclusion of a provision for coverage of renal patients, certain political considerations figured prominently. It has been apparent in the number and sponsorship of bills on national health insurance and on broad catastrophic insurance coverage that there is strong sentiment in Congress to approve some form of assistance for patients afflicted with highly expensive diseases. There was general agreement that the Long bill for catastrophic health insurance with a proposed budget of $3.2 billion a year would likely not pass through the Congress in 1972, particularly since the Social Security Amendments were already viewed as expensive. Therefore, Congress was willing to seriously consider supporting a provision for coverage of one condition, in this case end-stage renal disease, which would represent a small portion of the patient population and thus be significantly less expensive.

On the other hand, those who oppose this provision do so on the basis of two arguments. The first argument is that the costs for coverage under this provision are uncontrollable. An important assumption behind its passage was that cost containment could be achieved by organizing nationally the medical community that would be involved with the treatment of patients and instituting standardized reimbursement for specified services. However, it appears that there is a considerably greater range of costs for treatment than was originally contemplated by those urging enactment of the provision. The cost of treatment varies both from institution to institution and by mode of treatment. Estimates of the annual cost of hospital hemodialysis range from $10,000 to $40,000 per patient, and that of transplantation has been frequently cited as high as $45,000. In addition, not only is there a wide range in the fees for therapy, but also in the definition of essential services -- staffing ratios of hospital personnel, and the use of home hemodialysis, which would be cheaper than in-center treatment and, to some experts, much more effective. This indicates that it will be important that every effort be extended to develop incentives and mechanisms to control costs.

Augmenting the impact that the lack of standards for fees and services will have on the costs for treating kidney patients is the unpredictable effect of technological advances as to both basic techniques and reductions in mortality rates. Technology in this field is relatively new and is evolving rapidly, spurred on by the high cost of existing treatment, good-quality clinical research, and a significant number of patients who will die if not treated. Major extensions in the life-span of patients on hemodialysis without concomitant achievements in tissue transplantation or dialysis equipment could increase considerably the long-term costs attributable to this provision.

The second important argument against this provision is that it creates an inequitable distribution of medical resources. As discussed earlier, it has been argued that this is a rich nation that can afford to support health-care programs such as that for end-stage renal patients without requiring any severe resource constraints in other areas. On the other hand, it does not have unlimited financial and other resources. Besides the competition of health needs, there are competitions for funds for other socially important activities.

Limitations on funds for health do in fact enter into the decisions of how much money will be placed by the federal government into health care. And, since resource constraints are operative, equity questions emerge, particularly since the categorical approach for assistance to a small and discrete portion of the patient population may drain resources that could be used to assist larger segments of the population. The justice issue centers on the realization that patients with a certain specific disease condition requiring expensive treatment will be provided access to the health-care system, whereas many patients including those with equally serious conditions will be denied that opportunity.

Since this provision has already been enacted into law, the committee does not wish to take any position either for or against the expansion of Medicare to cover patients with end-stage renal disease. However, we do urge the Congress and the Administration to follow closely the administration of this provision, noting the overall costs and impact on medical manpower and facilities.

We are in unanimous agreement that coverage of discrete categories similar in kind to end-stage renal disease would be an inappropriate course to follow in the foreseeable future for providing expensive care to those who are unable to afford it. Among the many reasons for not following this disease-by-disease approach, we feel that two are particularly compelling:

The first of these relates to the effect that coverage of particular designated diseases would have on the total allocation of medical resources and the influence of that allocation upon equity. In addition to funds, other scarce resources such as medical personnel and facilities would be diverted from existing uses for treatment of a wide variety of medical conditions to provision of care for a relatively small number of patients with specially selected diseases. We believe the advantages of providing care for additional special categories of patients would be more than offset by the disadvantages and unfavorable results of such an arbitrary shift of health resources.

The second argument against the disease-by-disease approach to national health insurance is the indeterminate volume of diseases of this kind and the unpredictability of costs associated with these. One of the major inferences that can be drawn from passage of this provision is that additional legislation may be enacted to cover the provision of care for similar kinds of diseases. In fact, a bill has recently been introduced for providing coverage for the treatment of hemophiliacs. If this bill is passed and additional diseases are added, the committee believes that an immense skewing of medical resources may result, along with the creation of incentives for the development of even more technologies that would be highly expensive.

It has already been shown that the number of patients that may qualify for renal disease coverage has been imprecisely determined. Likewise, it can be shown that the number of patients with diseases that could be adequately treated through existing expensive technology is even more highly speculative. This uncertainty is compounded by the fact that at best the highly sophisticated medical technologies only partially restore patients to the normal-functioning state. The trade-offs would be such that money funneled into the development of these technologies would not be available for important areas of research that would get at the causes of these diseases and that would result in medical intervention that both would be less expensive and would avert any long-term disability. One wonders how many billions of dollars the nation would now be spending on iron lungs if research for the cure of polio had not been done.

In support of this position, consider the impact on societal resources if two additional diseases are covered through categorical national health insurance. The first of these, hemophilia,* would alone be quite expensive. An estimated 25,500 persons in the United States are being treated for severe and moderate hemophilia, which requires extensive medical care at an average cost of about $6,000 per year. The overall expenditure annually for the federal government would be roughly $150 million.

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*See attachment 1.

The cost of treating the second condition, end-stage heart disease,* by implanting an artificial heart would be considerably greater by virtue of the size of the patient population. The number of patients that would benefit from an artificial heart would range from 17,000 to 50,000 per year. Although the artificial heart is still in the experimental stages, it has been estimated that the cost of a nuclear-powered heart would be approximately $35,000 for a ten-year treatment period. This cost estimate assumes that the artificial heart functions ideally and creates no medical complications. With this in mind, our calculation brings the annual societal cost for the treatment of 17,000 patients a year to slightly less than $600 million. Taking the high estimate of patients, that is 50,000, the annual cost would be greater than $1,750,000,000.**

These figures are at best conjectural, for the likelihood of complications in this patient population, particularly among those requiring the artificial heart, would be very high. Nonetheless, it is apparent from the cost of both treatments that adding even a few more categories for support raises a concern as to whether or not they would require a disproportionate amount of the federal health budget.

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* See attachment 2.

** The figure $1,750,000 was arrived at by multiplying $35,000 by 50,000 patients per year, on the assumption that the entire $35,000 is paid the first year on a contract basis for the costs of the present value of implantation and ten years of patient maintenance.

We believe that we have enough information to make our conclusion that the categorical catastrophic approach should not be used as a means for providing expensive care to specific patient groups. We do not intend, however, to take a position on what approach, if any, would be appropriate, though we recognize that people could be assisted in paying for expensive diseases in various ways -- the categorical approach discussed in this document, an overall catastrophic approach, and through a universal health plan. Under any of these methods for handling medical-care expenses, the availability of resources in health for any one time period will likely not permit us to provide everyone with all the care that is technically possible.

We recognize that some may not agree with our position on the categorical approach and, therefore, recommend that before additional diseases are considered for coverage, the following studies be undertaken:

A. An assessment of technological advances that may be anticipated in the near future -- how much they may cost, and how effective they may be in rehabilitating patients. The most appropriate research method should be selected for this assessment, including, possibly, the Delphi method.

B. An examination of the capacity of the private sector to take up the costs of treatment for certain catastrophic conditions. Some information is already available from studies conducted by the Arthur D. Little Company, particularly with regard to renal dialysis. However, with the introduction of the artificial heart into the medical-care system, the impact on the private sector will be of a different order of magnitude. It might be valuable to assess the ability of the private health-insurance system to handle coverage of this condition -- the actual increase that would be required in premium rates, the extent of coverage, and the impact of the quality of care.

C. Comparison of the costs of various proposals for across-the-board catastrophic national health insurance with those of covering various specific catastrophic diseases on a categorical basis. This analysis should focus on the cost, the extent of coverage, and the benefits to the society at large -- numbers of patients involved, rehabilitation potential, etc. This should not imply endorsement of any type of catastrophic approach as the most appropriate path to national health insurance.

D. A close examination of the problem of determining the most effective allocation of funds for research and for the delivery of health services, and the benefits of both to society. This would include the question of whether or not to support research that will lead to expensive methods of treatment. Such a study should attempt to determine whether or not there are net advantages to be gained by placing more money into research to get at the etiology of disease and perhaps to affect larger portions of the population at significantly less expense, than into further technological development and use of known scientific information.

Attachment 1

National Blood Resource Program*

U.S. HEMOPHILIACS UNDER TREATMENT BY TYPE AND SEVERITY OF DEFICIENCY

Number of Patients

	Total	Factor VIII	Factor IX
Severe	14,421	12,117	2,304
Moderate	11,078	8,180	2,898
Total	25,499	20,297	5,202
Prevalence Rate	25.8	20.5	5.2

Distribution by Type of Severity

	Total	Factor VIII	Factor IX
Severe	56.6	59.7	44.3
Moderate	43.4	40.3	55.7
Total	100.0%	100.0%	100.0%

1971 FAMILY EXPENDITURES FOR HEMOPHILIA TREATMENT

	% Families	Families Who Had Expenditures		
	Reporting Expense	Average Spent/	Median Spent/	Maximum
Blood Products	34	$2400	≈ $900	$41,000
Other Related Care	48	$1000	≈ $630	$24,000
Total	60	$2000	≈ $760	$65,000

The costs now associated with replacement therapy have been brought down to the point where it is estimated that the hemophiliac requiring ongoing treatment may obtain it for an average cost of $6,000 per year.

* From: NHLI's Blood Resource Studies, June 30, 1972.

POTENTIAL CANDIDATES FOR ARTIFICIAL HEART REPLACEMENT AMONG PERSONS DYING OF HEART DISEASE UNITED STATES, 1969

HEART DISEASE DIAGNOSIS	DEATHS: UNITED STATES 1969	POTENTIAL CANDIDATES FOR ARTIFICIAL HEART REPLACEMENT			
		HIGH ESTIMATE*		LOW ESTIMATE	
		%	Number	%	Number
TOTAL	363,999	13.8	50,336	4.6	16,749
1. Ischemic heart disease without hypertension under age 65	151,948	16.4**	24,919	3.8**	5,774
2. Ischemic heart disease without hypertension, Age 65-74	157,494	11.2	17,639	2.6	4,095
3. Ischemic heart disease with hypertension under age 65	20,376	10.0	2,038	10.0	2,038
4. Other hypertensive heart disease under age 65	3,622	10.0	362	10.0	362
5. Rheumatic heart disease under age 65	8,978	25.0	2,245	15.0	1,347
6. Congenital heart disease under age 65	7,884	5.0	394	5.0	394
7. Other heart disease	13,697	20.0	2,739	20.0	2,739

Sources:

1. Deaths from National Center for Health Statistics (unpubl.), "Vital Statistics of U.S., 1969"

2. Note: Estimates derived from data of Framingham and Tecumseh studies.

* High and low estimates are based on implications of secondary disease conditions, development of effective emergency assist devices to allow extended survival in the terminal disease state, and ideal mobilization of best medical procedures now available.

** Estimates from Table 7 of Cardiac Replacement (A Report by Ad Hoc Task Force on Cardiac Replacement, National Heart Institute, 1969.)

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11. Bill: "Catastrophic Illness Insurance Act (S.1376)," introduced by Senator Russell B. Long, March, 1971.

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13. A study prepared by the Office of the Actuary, Social Security Administration: "Actuarial Cost Estimates for Medical Service Under Title XVIII of the Social Security Act for Patients Suffering from Chronic Kidney Disease"; documenting estimates prepared for the Congress, October, 1972.