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God Panels and the History of Hemodialysis in America: A Cautionary Tale

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In the words of economist Herbert Stein, “unsustainable trends cannot be sustained.” [1] We are currently spending \$2.7 trillion annually, or 18 percent of our GDP on health care in the United States. Conservative estimates indicate that the passage of the Patient Protection and Affordable Care Act (ACA) will save over \$200 billion by the end of 2016 [2], making the bold assumption that we can bend the cost curve downwards through a blend of preventive health care measures and new forms of capitated (non-fee-for-service) payments for health care services. Economists and policy makers will find that much can be learned about cost containment and its challenges from the Medicare-funded End Stage Renal Disease Program.

Recently the ACA established the Patient-Centered Outcomes Research Institute (PCORI) [3], which funds research designed to improve the quality of our health care delivery system, particularly identifying best-practice approaches that are evidence-based and applicable across economically and ethnically diverse populations. As it establishes policies to encourage the equitable dispensation of this country’s limited health care resources, PCORI’s experts will be able to evaluate the outcomes of the nation’s longest-standing entitlement program, the End Stage Renal Disease (ESRD) Program.

The ESRD Program’s Origins and Where It Stands Today

Established in 1972, the ESRD program proposed to cover treatment for end-stage kidney disease for all Americans eligible for Social Security [4]. The program was initiated in response to a Seattle policy during the 1960s that allocated access to hemodialysis, an effective but expensive treatment, on the basis of a patient’s social worth. At the time, James Shannon, director of the National Institutes of Health (NIH), wrote to the surgeon general about the “difficulties” created by innovations that delivered dialysis to patients with end-stage kidney disease: lives could be saved, but at a high cost to individuals and the country [5].

In 1962 the Seattle Artificial Kidney Center charged a committee of physicians, nurses, and community and civic leaders to develop an allocation system for dialysis treatments [6]. The committee agreed that “social worth,” an assessment of the patient’s anticipated contribution to society, would be the primary criterion for determining who would receive the life-sustaining treatment. Those individuals deemed highly valuable to society would receive dialysis, ostensibly to facilitate their physical rehabilitation and return to their jobs, families, and civic duties. Social worth, however, turned out to be just as subjective as it sounds, and bioethicists

immediately condemned the practice as highly discriminatory and derided the committee as a “God panel” [7, 8].

In response, a Committee on Chronic Kidney Disease, chaired by the renowned nephrologist Carl Gottschalk, convened in 1967 [4] and recommended federal funding for treatment of all patients with ESRD, assuming that most patients found medically suitable for dialysis would be under age 54 with few if any comorbidities. Rather optimistically, the committee estimated that approximately one in five ESRD patients would fall into the category of medically suitable. In light of escalating rates of renal failure affecting a broader economic swath of the electorate, Congress codified the lifelong subsidization of eligible patients with ESRD in 1972, through Public Law 92-603, signed by President Richard Nixon [5].

The fiscal implications of the Congressional decision were grossly underestimated. When the legislation was enacted, there were only 10,000 patients receiving dialysis, with an annual cost of \$280 million, but by 2008, there were 382,000 patients receiving dialysis, for a total cost of \$39.5 billion, accounting for 8 percent of Medicare costs [9].

The Gottschalk committee was wrong about much. Those on dialysis are not very likely to regain productivity and contribute civically. Dialysis does not necessarily result in workforce participation: a recent review of the United States Renal Data System database indicated there was a 71 percent unemployment rate *even among individuals aged 18-64* on dialysis. Additionally, non-Hispanic white men aged 30 to 49 years were significantly more likely to have the same level of employment after the initiation of dialysis as they did 6 months previously [10].

Furthermore, the elderly are now the largest and fastest-growing group with ESRD [11]. According to a cross-sectional study of the most recent National Health and Nutrition Examination Survey (NHANES), more than one-third of people aged 70 years and older have moderate chronic kidney disease, and the overall incidence of established ESRD in those aged 75 years or older has increased 67 percent since 1994 [12]. These older patients have more comorbidities and an increased risk of death from cardiovascular disease.

Despite decades of optimizing dialysis practices—more biocompatible membranes, refining dosage of dialysis, technological innovation in dialysis monitoring, and medical breakthroughs such as improved anemia control with erythropoietin stimulating agents—it has been difficult to document any improvements in patient survival [13]. The standardized mortality rate among those on dialysis has remained stubbornly unchanged at 20 percent for the past 20 years: 15 percent higher than in Europe even when controlling for the patient’s age and the presence of diabetes [14]. Moreover, the increased financial outlay for dialysis services and the remarkable technological innovations over half a century have not translated into improved quality of life on dialysis. Using a well-validated instrument to measure quality of life (Medical Outcomes Study Short Form 36 Item Health Survey), Gabbay and

colleagues found that between 1997 and 2006 there was no significant improvement in health-related quality of life among dialysis patients in the United States [15]. The elderly on dialysis have a greater threat of accidental falls than their age peers who are not on dialysis, experience a loss of independent functioning, and may develop progressive cognitive impairment [16].

Introduced with the noble intentions of restoring patient dignity and autonomy, the ESRD program has mushroomed into an unsustainable behemoth. Given the extensive evidence demonstrating unchanged quality of life and increased life-threatening complications for elderly dialysis patients, it is ethically justifiable to consider limiting access to hemodialysis and advocating nonaggressive renal care for the more frail elderly population. This was supported in a study by Chanda et al. [17], who found, that among patients older than 75 years with severe extrarenal comorbidities, dialysis did not confer a statistically significant survival advantage over nonaggressive, conservative renal care.

The quintessential questions in the rationing decision are:

1. What protocols guide the rationing of dialysis services?
2. Who makes the final decision to ration care?
3. How do we determine the level of disability and infirmity when assigning patients to treatment or nonaggressive care?

The tacit assumption has always been that the Centers for Medicare and Medicaid Services (CMS) would assume responsibility for making the guidelines that inform the rationing of any health care services. A 15-member Independent Payment Advisory Board [18] made up of doctors and medical professionals, economists and health care management experts, and consumers has been charged with finding ways to reduce the growth in Medicare spending. Paradoxically, that board is restricted by law from making any recommendations that involve rationing of health care [19]. It is possible that CMS's more cautious approach may in part be a response to the nefarious "death panel" rumor first espoused by former Alaska governor Sarah Palin, who opined that "the newly created health care legislation would create a death panel of bureaucrats who would decide whether Americans were worthy of medical care" [20].

So, for now, no one expects any serious health care rationing policy to emerge from the current combative climate on Capitol Hill. The answer may actually come from the community of renal specialists themselves. In a bold and responsible manner, the Renal Physicians Association and the American Society of Nephrology recently issued clinical practice guidelines on appropriate shared decision-making in the initiation and withdrawal of dialysis [21]. While these guidelines do not currently consider cost and do not explicitly endorse rationing, they are logical approaches in deciding how to ration health care.

Rationing need not be associated with the draconian image of patients dying in the streets for lack of care, but should be a highly reasoned and openly discussed

practice that assesses the risks of treatment for certain patient subgroups alongside the quality-adjusted life-year (QALY)—that is, the number of years of improved quality of life they stand to gain from medical interventions [22]. This utilitarian approach to optimizing resource allocation was embraced by the U.S. Panel on Cost-Effectiveness in Health and Medicine, composed of physicians, health economists, ethicists, and other health policy experts, who concluded that “QALYs provide a convenient yardstick for measuring and comparing health effects of varied interventions across diverse diseases and conditions” [23]. Stefanos Zenios and colleagues at the Stanford Graduate School of Business applied the QALY principle to dialysis patients. Their study showed that, for the sickest patients, the average cost of an additional quality-adjusted year of life was quite high—\$488,000 [24].

Although placing a cost on human life is a value judgment, the use of QALYs offers the advantage of standardization and fairness in deciding how to obtain the greatest health gains from our dwindling resources [25]. Perhaps to allay baseless fears of “death panels,” the Affordable Care Act precludes the use of QALYs in making recommendations based on benefit-per-intervention thresholds. It will take further courage from physician leaders and policymakers to adopt QALYs for measuring the cost effectiveness of medical interventions such as dialysis.

Without abrogating ethical principles, we can move forward with reasoned, evidence-based approaches to constrain health care spending. Reining in the cost of the ESRD program by providing nonaggressive care to patients with the highest morbidity would go far in proving to conservatives and liberals alike that reducing health care spending need not compromise the quality of health care. At the root of this argument is the inflated political rhetoric about rationing.

To be honest, rationing is already occurring in the care of dialysis patients. It occurs through the process of “cherry picking” [26], or dismissing from medical practices those patients who are chronically late for appointments, disruptive to staff or other patients, or nonadherent with their medical regimen. Payment systems that reward outcomes-based quality of care (pay-for-performance) and the bundling of formerly billable payments for ESRD services [27] could exacerbate the adverse selection or cherry picking in the health care market. However, when provider payments are adjusted for variations in the clinical complexity of cases (case-mix adjustment), pay-for-performance systems are steps in the right direction.

Renal care will continue to benefit from the widespread adoption of policies that identify individuals with multiple comorbidities, especially those older than 75, who could be assigned to nonaggressive medical management. In that context, QALYs are useful tools in cost-consequence approaches to medical decision making. While QALYs should not be the sole basis of medical decisions [28], they should be embraced as a fair method of curbing health care spending.

Perhaps most controversially, the government must decide whether it is now time to phase out the subsidization of care to all patients with ESRD and let patients under

age 65 seek insurance coverage from third-party payers. If the Medicare ESRD Program were restricted to patients 65 and older, shifting the insurance burden to third-party payers could save the program up to \$13.5 billion annually [29, 30]. The long-term fiscal benefit would be amplified if the ESRD Program adopted a mechanism to prevent or delay progression of disease, particularly diabetes and hypertension, in those under age 65.

We are already in the era of health care rationing, and the specter of “God panels” should no longer thwart our efforts to make prudent, ethical, and equitable decisions that are in the best interest of our patients and our country’s long-term fiscal health.

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