A new bill introduced by Congress in February 2016 aims to encourage living organ donations and protect the rights of living organ donors. The bill would also set the stage for education efforts on living organ donation to be instituted by the US Department of Health and Human Services.

The proposed legislation would prohibit providers of life, disability, and long-term care insurance from denying or limiting coverage to living organ donors. It would also prevent insurers from charging higher premiums. In addition, the bill clarifies that living organ donors may use time allotted to them through the Family and Medical Leave Act to recover from donation surgery and thus maintain their job security (Table 1).

“By creating job security for living organ donors and ensuring them time to recover from their donation surgeries, as well as ensuring education concerning these new protections, this important legislation will likely help countless Americans receive the gift of life,” said ASN President Raymond C. Harris, MD, FASN.

The number of people affected by kidney disease is staggering. According to the National Institute of Diabetes, Digestive, and Kidney Diseases, 1 in 10 American adults—more than 20 million people—are affected by some level of chronic kidney disease (CKD), and the numbers are increasing. A patient is added to the kidney waitlist every 14 minutes, and despite the fact that this list is always growing, living donation rates are decreasing. In all, 12 Americans die each day waiting for a transplant.

The Living Donor Protection Act of 2016 was introduced with bipartisan support by both houses of Congress, with Reps. Jerrold Nadler (D-NY) and Michael Burgess (R-TX) and Sens. Mark Kirk (R-IL), and Kirsten Gillibrand (D-NY) proposing the legislation.

The American Society of Nephrology was one of 16 kidney health organizations that united to advance the legislation on Kidney Community Advocacy Day in 2015. ASN will continue to work toward ongoing advances in technology and drug discovery continue to transform numerous aspects of health, but making such breakthroughs available to all who may benefit from them is often not possible, especially in the early days of their use. Furthermore, as society strives to address rising healthcare costs and consider responsible distribution of limited healthcare dollars, many questions arise regarding the most appropriate use of expensive tests and therapies.


“The medical research community is feverishly developing new technologies and drugs offering a plethora of treatment options; however, the existence of these treatments does not direct how and for whom they should be used,” said lead author Catherine Butler, MD, of the University of Washington. “Increasingly, medical practitioners, lawmakers, and laypeople take part in debate about this complex distribution. This discourse is best coordinated by participants understanding a common structure of ethical evaluation.”

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History of Hemodialysis
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Butler noted that because the themes explored in the history of dialysis are common and recurring among newly developed medical technologies, they may serve as a template for future discussion in parallel fields. As an example, the researchers highlight Medicare’s recently announced National Quality Strategy, which seeks to build a healthcare delivery system that’s better, smarter, and healthier. It includes 3 aims—better care for the individual, better health for populations, and reduced healthcare costs—that can only be reached by addressing multiple, and sometimes conflicting, values.

In their Ethics Series paper that considers the history of hemodialysis, Butler and her colleagues trace the ethical quandaries that arose at various times during the adoption and distribution of dialysis. “The first formal method of medical ethics grew up with the technology and set a precedent for many future medical resources,” Butler said.

Hemodialysis was conceived in the 1940s, but it wasn’t until 1960, when the Quinton–Scribner shunt (designed by Wayne Quinton and Belding Scribner, MD) allowed repeated vascular access, that creation of maintenance dialysis became feasible. In 1962, a committee of laypeople in Seattle attempted to fairly distribute a limited number of maintenance hemodialysis stations guided by considerations of justice. Later, as technology advanced, dialysis was funded under an amendment to the Social Security Act in 1972, and patients with end stage renal disease were entitled to receive Medicare benefits. With this change, the focus shifted to providing dialysis for all who needed it, which lessened the ethical stress of how to fairly distribute resources but created new questions such as how to balance longevity and quality of life and how to understand and respect patient preferences. Also, with funding available through Medicare, a growing number of older patients with comorbidities began dialysis, and utilization grew to the point that Dr. Scribner suggested the need for a “deselection committee” because the criteria for starting dialysis had become so liberal.

Butler’s team found that the 4 principles forming the basis of clinical ethics—beneficence, nonmalefice, autonomy, and justice—are emphasized to varying degrees over time. In the early days, the survival benefit offered by dialysis provided a strong argument for beneficence in initiating treatment, but it later became clear that the toll of treatment on quality of life sometimes outweighed the benefit, highlighting a role for the concept of nonmalefice. Also clear is that a well informed and autonomous person is in the best position to consider whether initiating maintenance dialysis will support his or her own values and preferences. Therefore, clinicians must ensure that patients receive adequate information and work together with patients to establish appropriate and individualized treatment plans. Finally, the authors note that recent scrutiny of healthcare spending has put a focus on the just allocation of limited Medicare funds, and the utility of dialysis is not simply being compared among kidney failure patients but also in the context of payments for coronary stent placement, supporting cancer research, or instituting preventive health programs.

“Through the history of hemodialysis, the 4 bioethical principles are weighed differently as forces of technologic innovation, resource limitation, and social values change,” said Butler. Because of this variability, creating sustainable ethical solutions may require considering and addressing all 4 ethical principles as fully as possible.

“I found the article very thorough and, to the best of my knowledge, very accurate. It is certainly one of the best expositions of one of the early bioethical dilemmas,” said Albert Jonsen, PhD, emeritus professor of Ethics in Medicine at the University of Washington’s School of Medicine. He noted that he and the late Dr. Scribner once talked about how commercial dialysis had become, and Dr. Scribner noted that he had often been asked why he didn’t patent the shunt. “He said he had never given it a thought, then went on to say that he deplored the formation of so many dialysis centers as their Palliative Care Medical Advisor.

The article, titled “The evolving ethics of dialysis in the United States: A principled bioethics approach,” is available at http://cjasn.asnjournals.org/content/early/2016/02/10/CJN.04780515.abstract.

Our physicians and scientists at The Mount Sinai Hospital’s Division of Nephrology are internationally recognized as authorities on the causes and treatments of all forms of adult and pediatric kidney diseases. Our kidney transplant specialists are investigating new ways to detect, prevent, and treat rejection that will have a lasting impact on the field. Our physicians are all on the faculty at the Icahn School of Medicine at Mount Sinai, which is ranked among the nation’s top 20 medical schools by U.S. News & World Report.

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