

Ethical Challenges in Nephrology Addressed at Kidney Week 2022

By Karen Blum

Watching the slow decline and death of a single mother with kidney disease who was an undocumented immigrant, only able to access dialysis emergently once a week per state policy, spurred physicians at the University of Colorado School of Medicine to conduct research that helped change policies at their local hospital and then at the state level to increase access to dialysis care for undocumented immigrants.

The inspiring tale was one of four presentations on ethical challenges in nephrology at Kidney Week 2022 and the focus of the Christopher R. Blagg, MD, Endowed Lectureship in Kidney Diseases and Public Policy, entitled Dialysis for Patients in the Undocumented Immigrant Community in the United States.

There are approximately 11 million undocumented immigrants in the United States, about 70% of whom lack access to health care coverage, said Lillia Cervantes, MD, director of immigrant health and an associate professor in the Department of Medicine at the University of Colorado Anschutz Medical Campus in Denver. Approximately 6000 undocumented immigrants in the United States experience kidney failure, and access to kidney replacement therapy for this community varies throughout the country.

After the death of their patient, named Hilda, Cervantes and colleagues were motivated to see changes in state coverage for the 78 other undocumented immigrants receiving emergency dialysis at their hospital every 7 days, as well as others throughout the state. To support their case, they began by conducting qualitative interviews of 20 immigrants, asking about their experiences receiving emergency dialysis (1). The team found that patients experienced significant psychosocial distress, having to wait for symptoms to build, sometimes eating high-potassium foods to meet admission criteria. Many patients had near-death experiences and had been resuscitated.

The team also conducted interviews with 50 clinicians in Colorado and Texas, asking about their experiences providing emergency dialysis (2). The physicians described emotional exhaustion from witnessing suffering and high mortality. Some reported feeling they were jeopardizing patient trust by having to turn them away or described how they gamed the system, overexaggerating patients' symptoms to get them care. Others reported physical exhaustion from trying to bridge care or numb themselves from feeling too much empathy and moral distress because they were treating patients based on immigration status, not medical factors.

Cervantes and colleagues also studied mortality differences between those receiving emergency dialysis and those receiving standard dialysis (3). They compared 211 patients, of whom 169 received emergency dialysis in Colorado and Texas, and 42 received standard dialysis in San Francisco. After adjustments, the mean 5-year relative hazard for mortality among patients receiving emergency dialysis was 14-fold greater.

Additionally, they looked at health outcomes and costs associated with end stage kidney disease in this population, pulling data from a Texas study (4) that compared patients who transitioned to scheduled dialysis—because of a grant mechanism that provided subsidies for private health insurance—with those who continued receiving emergency dialysis. Patients who transitioned to scheduled dialysis had six fewer emergency department visits per month and 10 fewer hospital days per 6 months, with a net savings of approximately \$6000 per person. An internal cost analysis of 78 patients found the

diagnosis-related group for severe life-threatening hyperkalemia was approximately \$6000 per weekly admission or \$24,000 per person per month vs. Medicaid reimbursement for standard hemodialysis of \$705 per week or \$2820 per person per month—an eightfold difference. Based on these data, the hospital's chief financial officer agreed that accommodating the patient population was more important than the financial incentive, Cervantes said.

The team presented their data to the Colorado Emergency Medicaid program, and in February 2019, the program expanded to include kidney failure as a qualifying condition to receive emergency Medicaid, covering standard, three-times-per-week dialysis care. A study evaluating approximately 30 patients before and 5 months after they transitioned to standard dialysis (5) found that although some patients had moderate anxiety about navigating the changes in care, they experienced relief in receiving consistent care. Investigators noted improvements in all five quality-of-life subscales, using the Kidney Disease Quality of Life Instrument Short Form 36 (KDQOL SF-36), as well as in seven symptoms using the Edmonton Symptom Assessment System.

The work has continued, Cervantes said. She coauthored a paper (6) describing the steps that each state can take to change access to dialysis care and worked with the National Kidney Foundation to write a letter to state Medicaid directors in support of expanded access to kidney replacement therapy, including living donor transplant. ASN was a co-signer. She also is working on a manuscript demonstrating the nearly \$13 million in cost savings for the state following the expansion of emergency Medicaid for the University of Colorado's 78 patients who are undocumented immigrants.

This year, the team gained access to home dialysis for the undocumented immigrant population and continues to push for additional legislation. New state bills provide subsidies to allow 10,000 undocumented immigrants to purchase private health insurance off the exchange and created the first state Medicaid program for undocumented immigrants under age 18, as well as for postpartum mothers.

"As clinicians, we're not traditionally trained to engage in advocacy or health policy change," Cervantes said. "We can each leave this world a better place like Dr. Blagg if through grit and perseverance we work toward health justice."

Shared decision-making

Another Kidney Week presentation, entitled Ethics of Shared Decision Making in Kidney Diseases, discussed the benefits and necessities of shared decision-making in advanced kidney diseases, a process now considered the gold standard for communication. In shared decision-making, clinicians and patients come together and try, through give and take, to optimize the patient's involvement in his or her care, said nephrologist Sara Davison, MD, a professor of medicine and bioethicist at the University of Alberta, Canada, and director of the university's Kidney Supportive Care Research Group.

The essential elements to this interchange (7) are that there are two parties involved and that they reach a decision by consensus. It means that one party cannot merely acquiesce, reluctantly agreeing to or passively accepting that decision, she said. Shared decision-making should be viewed as a collaboration in all aspects of clinical care, Davison said, and requires information, facts, values, and preferences from both the patient and clinician. "Only when both are actively considered and incorporated into

decisions can they be actively shared," she said.

The process should begin at the earliest point of the clinical encounter, she said, and the clinician and patient should share in what is being investigated, including determining what is the health problem, what matters most to patients and would be considered an adequate solution, what patients want to achieve, and what they are willing to do. Then, when focusing on designing health-outcome goals, keep them specific, actionable, reliable, achievable, and realistic.

Davison advised, when formulating an action plan with patients, consider the following factors:

- **Connecting:** Who are the most important people in a patient's life? How often can they see them?
- **Enjoying life:** What activities or hobbies make them happy? What do they find so important that they cannot imagine living without?
- **Managing health:** How important is symptom control? How do they feel about quality versus quantity of life?
- **Functioning:** How are they doing with self-care and independence? How do they feel about asking for help?

Then, when having a conversation about moving forward, make sure to ask if it is acceptable to talk about a patient's options, ask if the patient would like to hear what you consider the most reasonable medical options, assess if the patient agrees to any of the options, confirm that your understanding about the patient's choice is correct, and then plan for the next step, Davison said. ■

References

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