Serving the Underserved

The following article is the fourth of a five-issue series focused on caring for patients in underserved populations. Inspired by several sessions at Kidney Week 2023, this series features unique patient and physician perspectives, explains legal protections and limitations, and seeks to identify opportunities to improve kidney care for these communities.

By Bridget M. Kuehn

Improving Care Access and Research Are Key to Boosting LGBTQ+ Kidney Care

After being turned away by a physician because she was a transgender woman, a 56-year-old Black patient had not seen a physician in a decade but was seeking chronic kidney disease (CKD) care. The patient had elevated blood pressure, an estimated glomerular filtration rate (eGFR) of 20, and growing fatigue, according to a case presented by Dinushika Mohottige, MD, MPH, assistant professor at the Institute for Health Equity Research at the Icahn School of Medicine at Mount Sinai and the Barbara T. Murphy Division of Nephrology, New York, NY, at Kidney Week 2023.

“We are left with many questions in this case,” Mohottige said during the “We Are Never over the Rainbow: Nephrology Care for the LGBTQ+ Community” session at Kidney Week. “What is the impact of prior and current discrimination and structural inequities on the experience of seeking kidney care?”

The case reflects a common hurdle to care for transgender patients, 29% of whom report having been refused care by a clinician (1). These concerns often extend to other members of the lesbian, gay, bisexual, transgender, queer or questioning, plus (LGBTQ+) community as well, with 8% reporting they had been denied health care due to their actual or perceived gender identity. Presenter Yuvaram Reddy, MBBS, MPH, FASN, assistant professor and Director of Diversity, Equity, and Inclusion for the Renal-Electrolyte and Hypertension Division at the Perelman School of Medicine, University of Pennsylvania, Philadelphia, and other speakers at the symposium highlighted the importance of creating welcoming clinical environments, understanding the clinical implications of gender-affirming care, and engaging in robust, shared decision-making as ways to improve kidney care for LGBTQ+ patients.

They also emphasized the importance of engaging this community in research to help close knowledge gaps.

“You are your own ‘out’ gay person in his department. Addressing session attendees and speaking as part of the LGBTQ+ community, Reddy said, “We are still facing discrimination, and [members of the LGBTQ+ community] may fear it. Don’t make their fears come true. Help them feel like you are allies rather than accomplices in the system.”

Intersectional challenges

LGBTQ+ patients face many of the same barriers to health care as other marginalized groups, Reddy stated. Social determinants of health such as poverty, inadequate housing, economic and food insecurities, discrimination, and lack of insurance may all create barriers to access, he noted. For example, he said that one in three transgender adults has a household income below $25,000, and the same proportion has experienced homelessness in their lifetime (2).

“Remember that being a sexual or gender minority is not the risk factor,” Mohottige said. “It is actually a domain through which other key social determinants of health are allocated.”

“In a way, doing well in society and living a good life is really hard,” Reddy stated. “You have social determinants of health such as smoking (3) and obesity, among LGBTQ+ individuals (4). Stress caused by marginalization also increases cortisol and causes other physiologic changes that can affect overall health or kidney health, Reddy noted. “Increased smoking and obesity run the cascade of exacerbating CKD,” he said. “Because social supports may be lacking, home dialysis and transplant may be more challenging.”

For individuals who have multiple marginalized identities, these challenges are often compounded, Mohottige explained. For example, she noted that gender and sexual minority individuals who are also from racially minoritized groups face much higher rates of violence. Additionally, gender and sexual minority individuals who have disabilities are more likely to face employment discrimination or health care access challenges. “Discrete categories like race and gender don’t account for the multidimensional experiences of people experiencing simultaneous forms of marginalization,” she said. She noted that it is important to acknowledge individuals’ experiences and recognize how policies and social structures may affect them.

Despite recent progress in the United States, such as securing the right to same-sex marriage in 2015, equality for LGBTQ+ people have come under attack with discriminatory laws passed in 25 states that are home to 40% of the LGBTQ+ population, Reddy said (5). The same number of states has laws specifically targeting the rights of transgender individuals.

“With every step forward that you take with communities, there are sometimes steps taken back,” he said.

Reddy stated that such laws make people feel unsafe. For example, a 2022 survey by The Trevor Project, a nonprofit organization, found that nearly half of LGBTQ+ youth had considered self-harm in the past year (6). The survey also found youth with support from their family had half the rate of suicidal ideation as individuals without such support, but fewer than one in three transgender or nonbinary youth reported they had such support. Supportive schools and communities were also protective. “Having affirming folks in your life helps substantially,” Reddy said.

Cultural humility

Too often, when LGBTQ+ individuals seek health care, they may find their clinicians are unprepared to provide safe and affirming care, which affects their ability to trust the medical system, Reddy noted. Two-thirds of transgender adults report worrying that their health evaluations will be affected by their sexuality or gender identity (2). Half of transgender adults report negative or discriminatory experiences with the health care system. “There is a large sense of mistrust, and that mistrust is not misplaced,” Reddy said. “We should be more supportive and inclusive.”

Reddy noted failure to inquire about sexual orientation or gender identity may make patients feel they cannot share information about their lives or partners. Instead, they may report living alone and not having someone who could help with home dialysis or be a living donor. Creating a welcoming environment can help patients feel psychologically safe. He suggested examples such as routinely collecting sexual orientation and gender identity
information in a non-judgmental way; learning and respecting pronouns and proper language when referring to patients and/or their partners; providing all-gender, single-user bathrooms; and displaying Pride (a celebration of LGBTQI+) flags or pins. He acknowledged that physicians may not always feel prepared for conversations about gender or sexuality, but training and cultural humility can help.

“Cultural humility is really important and being okay with not having all the answers, being okay with making mistakes and learning through the process,” Reddy explained. “With the right training, we could create a welcoming environment to invite the opportunity to talk about these issues. That’s okay. But many people are willing to talk about it and don’t feel like we are creating space for them.”

Because sexual orientation and gender identity data are not routinely collected in many clinical and research settings, there are significant gaps in data on this population. Reddy noted that fewer than 1% of National Institutes of Health-funded projects focus on LGBTQI+ individuals. Mohootige recommended engaging LGBTQI+ individuals at every point in the research process and designing better health care systems. “We need to center the expertise of both our patients and our providers,” he said. “Don’t think of it as a starting point because that is where so much knowledge is inherently embodied,” she said. Reddy also emphasized the importance of collective and individual advocacy. He noted ASN’s decision to hold Kidney Week in Florida in 2022 and “bring ASN’s [supportive] values to the state, which had recently enacted a bill prohibiting the discussion of sexual orientation or gender identity in schools. During the meeting, ASN and its members donated approximately $35,000 to the onePulse Foundation, a local LGBTQI+ charity, he said.

Reddy noted that until 1973, the Diagnostic and Statistical Manual of Mental Disorders listed homosexuality as a mental disorder. However, advocacy by LGBTQI+ individuals and psychiatrists, such as John Fryer, MD, who had been removed from his residency at the University of Pennsylvania for being gay and was fired by another hospital for his advocacy, helped change that (7). “Individual advocacy has a strong place here, and there’s good trouble to get into,” Reddy explained. “Sometimes it is with consequences, but it can leave a long-term impact for generations.”

Clinical considerations

Sex is frequently a variable used in clinical decision-making tools. However, clinicians may rate based on the patient’s circumstances. She said that this is particularly important when a patient’s eGFR on one of the calculations crosses a clinically important threshold. “We put a lot of weight on this number, even though we recognize how much uncertainty there is,” she said. For example, she highlighted the case of a 55-year-old transgender woman who presented to a transplant center for evaluation with well-controlled diabetes and hypertension. In addition to metformin and nifedipine, she was taking estradiol and spironolactone. Using the CKD-EPI equation with creatinine alone with a male coefficient, the patient had an eGFR of 20. With the female coefficient, she had an eGFR of 19. However, with the CKD-EPI with cystatin C alone, the patient’s eGFR was below 20 with either gender coefficient. Farouk noted that a patient taking exogenous estrogen may potentially be at increased risk of pulmonary embolism or deep vein thrombosis (DVT) when immobilized after surgery (15). “Transdermal preparations may be better [than oral ones] in this context [transplant surgery], not only for those with CKD but also perhaps for those preparing to undergo any surgery,” she said.

Farouk noted that research in cisgender women that showed that taking estrogen-containing oral contraceptives activates the renin-angiotensin-aldosterone (RAS) system because it must be first metabolized by the liver (16). Transdermal application of estrogen-containing contraceptives, however, circumscribes the liver and is not associated with as much RAS activation, which may be better for patients with CKD.

“There [are] no data to support routine perioperative discontinuation of gender-affirming hormone therapy, and this decision needs to be the result of shared decision-making, and the risks and benefits need to be discussed, including the impact of discontinuation on [a patient’s mental health],” Farouk added. “Perhaps for this particular patient, stopping hormone therapy [would have been] more harmful than this theoretical risk of developing DVT.” Farouk also recommended shared decision-making with transplant patients who may be considering the risks of future gender-affirming surgeries and their potential impact on the allograft or discussing the optimal timing of surgeries. She said clinicians use the same process for transplant patients considering any future surgeries. Farouk emphasized the importance of clinicians learning about gender-affirming therapies and connecting with experts on trans gender care.

“It is our role to become comfortable and familiar with [gender-affirming therapy and its effects] so we know what the right questions are to ask and know where to go when we need help,” Farouk said.

References


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