ALLIANCE FOR HOME DIALYSIS

2021 National Policy Roundtable

A Dialogue on Disparities, Systemic Inequities, and Access

Context

Although the burden of kidney disease is felt in all communities across the country, the degree of burden differs significantly depending on socioeconomic, cultural, political, and geographical factors. Research shows that certain populations – including, for example, African American and Hispanic communities – are disproportionately affected by chronic kidney disease (CKD) and possess a much higher risk of developing kidney failure. In fact, while African Americans make up about 13% of the population, they account for 35% of Americans with kidney failure.[1] Similarly, when compared to non-Hispanic Caucasians, Hispanics and Native Americans also have an increased risk of being diagnosed with kidney failure.[2] In these communities, there are a number of systemic barriers that limit access to the important health care knowledge and resources needed to effectively address issues stemming from kidney disease. The knowledge and resource gap likely stems in large part from a lack of access to care, as studies have found that 1/3 of Hispanics, 1/3 of Native Americans, and 1/5 of African Americans are uninsured.[3]

Data make clear that, in the United States, people of color also have less access to home dialysis therapy. Nationally, Black patients were 30.1% less likely, and Hispanic patients were 7.6% less likely, than white patients to start on peritoneal dialysis (PD). Similarly, for home hemodialysis (HHD), Hispanic patients are 42.1% less likely, and Black patients are 9.8% less likely, to receive HHD, on average.[4] Further, access to pre-dialysis nephrology care or having insurance are both less prevalent among minority patients.[5] Addressing these disparities is key to ensuring that every American has equal access to high-quality kidney care, including the choice to dialyze at home if medically appropriate. In the case of patients with kidney failure, this means working to ensure equal access to the optimal dialysis modality for each patient.

While these disparities have always merited attention, the COVID-19 pandemic's social distancing needs have further highlighted the need for increased access to home dialysis for all populations. According to the Centers for Disease Control and Prevention (CDC), not only are

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[1] https://www.niddk.nih.gov/health-information/kidney-disease/race-ethnicity

[2] https://www.usrds.org/media/2283/2018_volume_2_esrd_in_the_us.pdf

[3] https://www.kidney.org/atoz/content/minorities-KD

[4] *Distribution of Dialysis Patients Utilizing Home Modalities in 2018 by State*, the Moran Company

[5] https://www.healio.com/news/nephrology/20200219/home-dialysis-use-varies-by-race-largely-due-to-socioeconomic-factors#

people of color more likely to experience kidney failure, they are also more likely to experience serious COVID-19 complications and even death once infected.[6] Similarly, patients with pre-existing kidney disease are at dire risk of experiencing a severe illness or mortality stemming from COVID-19.[7] In fact, patients on dialysis who develop COVID-19 experience an astonishingly high short-term mortality rate of 20% or greater.[8] However, ESRD patients who dialyze at home are afforded an important opportunity to avoid COVID-19 exposure by doing their treatments at home, where they can social distance and avoid potential exposure through traveling to the dialysis clinic or doctor's office. According to a study conducted in New York during the initial months of the pandemic, home patients were less likely to test positive or be hospitalized for COVID-19 than in-center patients.[9] This result perhaps reveals the protective effect of home therapies.

Against this unique backdrop, the members of the Alliance for Home Dialysis (the Alliance) Steering Committee saw a critical opportunity to convene members of the kidney community and associated stakeholders to identify policy priorities for advancing health equity and home dialysis both during the pandemic and beyond – such as (1) empowering patients to deal with planned and unplanned dialysis starts; (2) strengthening the kidney care workforce; and (3) expanding access to quality care through telehealth and remote monitoring. The Alliance, a coalition of patient, clinician, provider, and industry voices that shapes and advances national policies and programs affecting home dialysis, brought members of the community to collaborate and share recommendations, evidence, and policy concerns at a roundtable known as the Home Dialysis National Policy Roundtable: A Dialogue on Disparities, Systemic Inequities, and Access. The following provides a recap of the roundtable, including major themes and opportunities for further action through policy change.

Proceedings

Over 100 experts in the field of kidney disease care –clinicians, doctors, academics, policymakers, and patient advocates – assembled virtually on February 25th for the Alliance's 2021 Home Dialysis National Policy Roundtable: A Dialogue on Disparities, Systemic Inequities, and Access.

The roundtable consisted of panel discussions and presentations, as well as both written and on-camera question and answer sessions with the audience. Speakers on each panel included current and former dialysis patients, preeminent researchers, frontline clinicians, distinguished members of clinical societies, policymakers from the Centers for Medicare and Medicaid Services (CMS) and congressional staff.

Four sessions, with the following distinguished speakers, were featured:

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[6] https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html

[7] https://pubmed.ncbi.nlm.nih.gov/32247631/

[8] https://www.kidney-international.org/action/showPdf?pii=S0085-2538%2820%2931203-5

[9] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7685041/

- **Overview of Health Disparities and Inequity in Dialysis: Framing the Discussion**
    - Dr. Marjorie Innocent, NAACP
    - Dr. Mallika Mendu, Brigham and Women's Hospital
- **Empowering Patients in Both Planned and Unplanned Starts**
    - Dr. Maggie Gellens, Baxter Healthcare
    - Miriam Godwin, National Kidney Foundation
    - Dr. Vesh Srivatana, Rogosin Institute
    - Dr. Mourad Alsabbagh, DHR Health
    - Dr. Eric Weinhandl, U.S. Renal Data System
    - Dawn Edwards, HHD patient
- **Overcoming Barriers to Home Dialysis Related to the Clinical Workforce**
    - Dr. Page Salenger, Dialysis Clinic, Inc
    - Amber Pettis, former PD patient and kidney transplant recipient
    - Dr. David Ellison, American Society of Nephrology
    - Lucy Todd, Baxter Healthcare
    - Lillian Pryor, American Nephrology Nurses Association
    - Dr. Janice Lea, Emory University
    - Lauren Oviatt, CMS
- **How Advances in Technology Can Increase Access to Home Dialysis and Quality of Care**
    - Kyle Hill, Congressional Kidney Caucus
    - Dr. Rebecca Schmidt, Renal Physicians Association
    - Dr. Eric Wallace, University of Alabama at Birmingham
    - Tracey Amadi, HHD patient
    - Dr. Mike Kraus, Fresenius Kidney Care, Inc
    - Dave Icke, Humana

Through the four sessions the speakers, discussants, and attendees discussed how the kidney community, working in conjunction with policymakers, can work to reduce disparities in kidney care, empower patients, reduce and mitigate unplanned starts, increase clinician education and recruitment of clinicians interested in home dialysis, and support advancements in technology, such as telehealth. Throughout the day, speakers focused on the need for further inquiry and collaboration in order to create change both during the COVID-19 pandemic and after it is over.

Session 1 – Overview of Health Disparities and Inequity in Dialysis: Framing the Discussion

The Roundtable began with a framing discussion on the current state of play related to health inequities in the kidney community, including the long-standing racial inequities, which have increased during to the COVID-19 pandemic. According to Dr. Malika Mendu, a nephrologist with Boston's Brigham and Women's Hospital, these inequities include a range of issues related to kidney disease, from the initial education (or lack of education in many cases) about ESRD to home dialysis to kidney transplants. Dr. Marjorie Innocent, Health Policy Director of the NAACP, confirmed the troubling reality that the adverse health outcomes from COVID-related complications were not unexpected as minorities have not been provided adequate resources to address their health issues successfully during the time of COVID-19. She explained that this is symptomatic of how the US healthcare system functions; the focus on managing health may mean that there is insufficient attention to preventing disease in the first place. Both Dr. Mendu and Dr. Innocent agreed that now is the time to make headway to address the inequities of kidney care.

According to both Dr. Mendu and Dr. Innocent, the first means of addressing any issue is to recognize the problem. The kidney community (policymakers, advocates, industry, etc.) needs to understand the urgency of this issue so that multiple stakeholder sectors can align to confront the issue.

Specifically related to policy change, Dr. Mendu mentioned that the Trump administration's Advancing American Kidney Health Initiative (AAKHI) lays out solid goals, but said the community needs to figure out how to achieve these goals in a manner that is equitable. Measuring the impact of payment models included in AAKHI to understand their impact on disadvantaged communities will be critical to this effort, Dr. Mendu said, applauding the Biden administration's January executive order asking federal agencies to first measure how care is being delivered to disadvantaged communities, and then implement an action plan to solve evident issues. With regard to improving uptake for home dialysis in minority communities, she explained that the good news is that providers and patients on the frontlines have already pointed to solutions: we need earlier referral to nephrologists, earlier education, and assurance that providers and patients have the resources they need.

Beyond better measurement and increased resources, the conscious removal of structural barriers must be part of any successful health equity effort. Dr. Innocent asserted that an approach focused on prevention requires not only increased education for and outreach to patients, but also needs to address social determinants of health. Appropriate investment in education, housing, transportation, etc. will help augment overall health, especially for marginalized people. Dr. Mendu proposed that nephrologists can help by first considering and recognizing the structural barriers facing patients of color.

Session 2 – Empowering Patients in Both Planned and Unplanned Starts

Setting the Stage

The second session of the day focused on why so many patients "crash" into dialysis in an unplanned manner and what can be done to ensure that patients who begin dialysis, whether through a planned or unplanned start, are granted the opportunity and ability to dialyze on their own terms.

Before the panel discussion commenced, Miriam Godwin from the National Kidney Foundation (NKF) presented preliminary results from an NKF survey designed to help the community understand disparities in home dialysis, including why Black patients are less likely to utilize home dialysis than white patients. Results from the survey show that providing education outside the traditional healthcare setting may play a role in closing the racial gaps in home dialysis access. Additional analysis on other variables, including education, insurance status, and income, should be conducted to ascertain how these factors influence home dialysis uptake, she noted.

Panel and Discussion

Following Ms. Godwin's presentation, nephrologist Dr. Mary Gellens of Baxter Healthcare began a Q&A panel with nephrologists, patients, and other experts to dive further into the questions of what happens during an unplanned dialysis start, how COVID-19 has impacted dialysis starts, and what can be done to increase home dialysis during this time.

Patients with kidney failure who "crash" into dialysis experience a number of adverse outcomes associated with an unplanned dialysis start, including economic burdens and a higher risk of mortality. Not only are unplanned starts more costly and dangerous for patients, but they may also lead to pressured and uninformed decisions that will negatively affect patients throughout their dialysis journey. Dawn Edwards, a home dialysis patient, shared that when she crashed into dialysis, her physician steered her away from a home modality, thinking it could lead to infection. In-center dialysis significantly lowered her quality of life, Ms. Edwards said, noting she has since learned that home dialysis is actually the ideal option for her. Many other patients in the audience commented that they were similarly advised to avoid home dialysis, a directive that negatively impacted them. All speakers agreed that the community must work together to reduce unplanned starts, and when patients do experience them, they must be given all options.

This brought Roundtable participants to a discussion of why unplanned starts occur and what can be done to reduce them. The group heard that an unplanned start may be the result of a myriad of factors, but many agree that it comes down to a lack of education and access to kidney care. Dr. Vesh Srivatana of the Rogosin Institute shared that someone who experiences an unplanned dialysis start also likely experiences other disparities in kidney care, such as lack of nephrology care at all. He added that the occurrence of a planned, versus unplanned, start is an extension of the inequity issue at large.

Through the discussion, the audience learned that large numbers of unplanned starts can be prevented through policy changes, increased education, and better access to nephrology care. Dr. Mourad Alsabbagh of DHR Health observed that primary physicians to be better educated about early warning signs so that they may refer patients earlier, helping patients prepare for planned starts to dialysis. The opportunity to utilize primary care physicians to fill these upstream gaps was widely echoed by the audience. Nevertheless, some patients will likely still crash into dialysis – and therefore, will be required to make life-altering decisions under adverse conditions (e.g., in an emergency room, under distress, in a short amount of time). The emergent hospital setting for dialysis patients strongly lends itself to an in-center approach, and so these factors together present a huge barrier to access to home dialysis.

To overcome these barriers and improve home dialysis access and uptake, a combination of changes must be sought, panelists shared. Dr. Srivatana proposed aligning policy incentives to move people toward home dialysis and improving patient education about different dialysis options. He shared that one of his recent patients was not even aware of home hemodialysis. David Rush, a home dialysis patient, emphasized the need to increase patients' awareness of home dialysis, adding that nephrologists need to follow up with patients regarding dialysis options beyond the initial emergency room visit. To make these changes, the community will need buy-in from different levels (medical, administrative, nursing, etc.) to coordinate movement towards home dialysis and build out the infrastructure to support home patients. But, according to Dr. Srivatana, "you build it, and they will come."

As far as home dialysis policy is concerned, Dr. Eric Weinhandl of the U.S. Renal Data System (USRDS) added that we may need to consider acute kidney injury (AKI) issues in the planned/unplanned start conversation. Because Medicare does not reimburse for home dialysis for AKI patients, those patients – many of whom are recovering from COVID-19 – miss out on an important opportunity to recover at home, in a socially distanced fashion. To increase home dialysis utilization, he offered that we may need to put mechanisms in place like transitional care units that allow people to become more familiar with home dialysis, and to chart a path to transition more people to home therapies.

The purpose of supporting and empowering patients is ultimately to enable them to travel through dialysis on their own terms, discussants agreed. An important aspect of this is adequately preparing them – including proper education and information about care options – so that dialysis starts can more often be planned and that they can choose the modality that is right for them. While the Alliance has always supported increased patient education options, there is more to be done, including potential innovative solutions like apps and novel ways to get information to patients through technology.

Dialysis patients on the panel agreed that their quality of life improved when they felt empowered to drive their own dialysis choices. Dawn Bates, a care partner to her husband, stated that home dialysis has allowed her husband to determine his own path forward, while Mr. Rush shared that it allows him to spend more time in the comfort of his home with his family. Dawn Edwards, who had been dissuaded from utilizing home dialysis, was finally encouraged to seek out information on home dialysis, and when she finally made the switch, she said it greatly improved her quality of life.

One theme that also emerged, however, is the reason to be optimistic: recent data demonstrates that some of these barriers are beginning to erode slightly, and that there is movement toward greater uptake of home dialysis. During the panel, the audience had the opportunity to learn how the AAKHI and the COVID-19 pandemic has increased home dialysis uptake, which was alluded to by Drs. Mendu and Innocent. Dr. Weinhandl explained that since the AAKHI was implemented, more people have been utilizing PD. In fact, he said that during the initial COVID-19 surge last year, a peak of around 18%-19% of patients were on the PD therapy, several percentage points higher than the typical. He added that year after year, PD is growing at a rate of approximately 10%.

Session 3 – Overcoming Barriers to Home Dialysis Related to the Clinical Workforce

The third session of the day focused on nephrology workforce development issues for providers (primarily nurses and nephrologists) in the kidney care and home dialysis space. This panel explored issues that obstruct clinicians from providing home dialysis; barriers related to clinician education; how the pandemic and policy changes have affected the nursing profession; how to better recruit quality nephrologists, particularly nephrologists of color; and CMS's agenda related to implementing policy proposals, including the ESRD Treatment Choices (ETC) model.

On the provider side, several impediments to utilization of home dialysis were flagged, including a nephrologists' knowledge of the home modality. Dr. Ellison of the American Society of Nephrology shared that there is significant variability in the uptake of home dialysis from state to state, likely driven by physician comfort with home modalities. He suggested that, to reduce variation, there must be change in how nephrologists are educated, trained, and what they are exposed to (such as home dialysis), so that uniform, optimal care can be delivered. Similarly, Dr. Ellison suggested that training guidelines should be revised to specify home dialysis training in clinical guidance. Additionally, Dr. Ellison promoted the value of physician-champions who advocate for home dialysis to expand exposure to and knowledge of home dialysis.

In the kidney care space, speakers discussed longstanding difficulty with recruiting medical students and future doctors into the nephrology field. Some commenters claimed that nephrology is not as "sexy" as comparable specialties, while others argued nephrologists are not compensated enough. While other specialties are known for surgical procedures, nephrology has seen challenges in recent years in this area, specifically related to the need for more clinicians to be trained to place PD catheters. Further, many attendees identified nephrologist recruitment as a continuing issue to growing the talent and breadth of the kidney care workforce. Still, many panelists offered policy approaches that they believed would help overcome these challenges:

- Dr. Ellison observed that to recruit more nephrologists by making the profession more attractive, a specialization training track can be operationalized, including a strong emphasis on home therapies.
- Lillian Pryor of the American Nephrology Nurses Association added that offering more rotations in clinical settings could attract additional students.
- Dr. Janice Lea of Emory University agreed with Ms. Pryor that exposure, especially early in the process, is an important facet to recruiting for the nephrology profession. Dr. Lea said we should expose prospective nephrologists to "good" outpatient and home dialysis outcomes to better entice these students.

- Dr. Lea also shared that, similar to other professions, improved pay and reduced student debt may attract more individuals.

Dr. Lea reminded the group that serious challenges remain in recruiting nephrologists of color. She mentioned a stark gap between the number of nephrologists of color and the number of minority patients suffering from CKD, noting that additional nephrologists of color will help address health disparities in the kidney community by improving the engagement of patients and promoting trust of care providers. On the other hand, it is key to ensure that regardless of race, nephrologists are adequately prepared to prescribe home dialysis. As Eugene Jackson, a PD patient, said, while it is comforting to have a nephrologist that looks more like you, what matters most is a doctor's ability to provide quality care.

As concerns regarding the recruitment of nephrologists were voiced, so too were issues about the nursing workforce shortage. Lucy Todd of Baxter and member of the ANNA board, identified two main components to the problem: (1) there is a faculty shortage, so schools cannot accept all the people who want to go to nursing school; and (2) there is a lack of exposure to actual dialysis and clinical-setting kidney care in nursing school. She added that the first issue most likely requires a federal solution, while the second may be solved by establishing an elective program during earlier schooling that promotes exposure to care for ESRD patients, including at CKD clinics. While Ms. Todd stated that COVID-19's impact on nurses in home programs has been relatively modest, she cited a startling statistic from USRDS data showing that in-center patients are hospitalized from COVID-19 three to four times more frequently than home patients. Ms. Todd also reminded the audience that the community confronted issues early in the pandemic related to allowance of surgeries for PD catheter placement, an issue that the Alliance for Home Dialysis previously raised with CMS.

Lauren Oviatt, a representative from CMS, shared that the agency continues to consider policies and guidance directly related to home dialysis community. Attendees were interested in what CMS needs from the kidney community to move the needle more forcefully on policies that will address barriers to home dialysis. Ms. Oviatt said that at the staff level, CMS may be supportive of some policies, but that congressional action is needed to achieve many of the workforce policy ideas floated by our moderator and audience.

Session 4 – How Advancements in Technology can Increase Access to Home Dialysis and Quality of Care

The fourth and final session of the day covered technologies that can improve the quality of, and access to, kidney care – specifically telehealth and remote patient monitoring.

Report from Congress

Following the onset of the pandemic, telehealth once again became a hot topic on Capitol Hill as the necessity for social distancing and stay-at-home orders proliferated. Members of Congress from both sides of the aisle have voiced support for improving access to telehealth so that Americans across the country –urban and rural – can obtain necessary care whenever and wherever they may need it. Kyle Hill, a staff member who advises the Chair of the Congressional Kidney Caucus, Rep. Suzan DelBene (D-WA), began this session by sharing that the bipartisan Kidney Caucus is currently focused on a number of telehealth policies to augment kidney care. Some of the Caucus' priorities, he said, include a continued push for more home dialysis, more funding for the KidneyX initiative, and improvements in payment models to improve transplant rates and home dialysis uptake. Mr. Hill stressed the importance of keeping Congress updated on insights and challenges coming from the kidney disease community.

Panel and Discussion

Like members of Congress, the kidney disease community has been broadly supportive of improving access to telehealth and remote patient monitoring, including through policies implemented during the pandemic. Dr. Eric Wallace of the University of Alabama at Birmingham shared that during the pandemic, telehealth and remote monitoring allowed people to receive care in their home, reducing the chances of contracting COVID-19 at the clinic.

Though new telehealth policies have largely augmented quality of life for dialysis patients, Dr. Michael Kraus, of Fresenius Kidney Care, cautioned that these policies need some guardrails need to be carefully tailored to ensure against abuse and brought up the point that unfortunately, disparities are also seen in access to technology. For example, not all patients have access to adequate internet access or devices; some patients told stories of having to use public broadband sources to connect with their doctors via telehealth or being unable to afford necessary home internet. Policy changes are needed in order to ensure that all patients can utilize telehealth.

More examples from the discussion include:

- Panel moderator Dr. Rebecca Schmidt of West Virginia University and the Renal Physicians Association shared that a lack of an infrastructure and knowledge regarding how to use the technology (e.g., smart tablets) present issues for her patients.
- Dave Icke of Humana said that from a payer and healthcare delivery perspective, reimbursement levels for telehealth services remain an issue to ensure that proper financial incentives exist to provide options for care.
- Other impediments mentioned by panelists and discussants include access to the necessary technology to conduct telehealth visits and connectivity/broadband issues.

Discussants Liz Ramos and Dale Rogers, both of whom are dialysis patients shared their first-hand experiences with one or more of these barriers. To help patients like them, they and others urged, the kidney community should take advantage of the current political landscape and widespread support for new telehealth measures to guide policy ideas that positively benefit the kidney community.

Conclusion

For each of the panels described above, profound learnings are paired with urgent questions. It became crystal clear through the day's sessions that the COVID-19 pandemic has exacerbated both the disparities faced within the kidney community regarding access not only to home dialysis, but also to basic kidney disease education and care. All patients deserve the option to dialyze at home if clinically appropriate, especially during a time where social distancing is required. Policy changes, discussed in detail above, may be appropriate, or even required, in order to ensure that patients can access appropriate services and modalities in order to reduce the numbers of unplanned starts and that adequate numbers of clinicians are educated in home dialysis and confident in prescribing the therapy. By creating changes in these areas, the community can begin to reduce the disparities that were discussed in relation to access to care, education, technology and other impediments to home dialysis.

Overall, it was also evident that participants were eager to continue exchanging ideas and sharing their experiences, as well as finding ways to collaborate on advocacy initiatives like many suggested in the proceedings. Speakers and attendees alike echoed the point that, given the urgency, we need to act to form and activate policy solutions to address health disparities for patients with kidney failure, bringing together patients, clinicians, academics, clinicians, payers, and policymakers to drive policies that will continue to lower barriers to access for home dialysis.