

National Institutes of Health

**Empowering Home Dialysis Workshop
Virtual
June 2–3, 2021**

SUMMARY REPORT

WEDNESDAY, June 2, 2021

Welcome from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Robert Star, M.D., NIDDK

Dr. Robert Star, Director, Division of Kidney, Urologic, and Hematologic Diseases (KUH), welcomed participants to the Empowering Home Dialysis Workshop and thanked the planning committee for organizing the meeting. He reminded participants that maintenance dialysis started in-center, transitioned to in-home therapy, and then migrated back to in-center. Home dialysis in the United States is the opposite of in-center dialysis and consists of two types: hemodialysis (HD) and peritoneal dialysis (PD). Home dialysis provides patients more control of their lives, with greater emphasis on the patient’s voice. This approach, however, shifts some of the burden to patients, but with reduced support for the procedure. Although the current U.S. target goals for establishing home dialysis are low, the new national goal of 80 percent may be too high. The aim is to determine sufficient goals that meet patient needs and U.S. guidelines and policy. The NIDDK, through this workshop, hopes to understand the state of home dialysis and the barriers to its uptake from the various perspectives represented.

Workshop participants also will be hearing from patients, learning from other health care systems, and reviewing various technological approaches. During the 2-day workshop, the agenda will consist of a patient panel to first identify the critical patient needs and how to reduce the burden of home-based dialysis to make progress in increasing use of this treatment modality. Workshop participants will address key questions during presentations and in breakout groups that touch on four main areas and key questions:

- I. Patient Needs
 - a. What does a patient want and need for an optimal home dialysis experience?
 - b. How does the diversity of where they live and what their homes look like factor into this experience?
- II. Social Determinants of Health (SDoH)
 - a. What are the SDoH and how might they affect dialysis utilization?
 - b. What can the field do to mitigate adverse SDoH?
- III. Technological Advances
 - a. How might technological approaches—such as those that minimize the footprint and storage needs of dialysis equipment and supplies—improve home-based dialysis?
- IV. Education and Training
 - a. How can education and training be used to help patients understand home dialysis and ways to perform it safely at home?

Dr. Star expressed appreciation to the planning committee for this innovative workshop design and to the presenters and patients for their support of this meeting.

Overview of the Workshop

Kevin Abbott, M.D., M.P.H., NIDDK; Eric Wallace, M.D., The University of Alabama at Birmingham (UAB)

Dr. Kevin Abbott welcomed participants and acknowledged the planning committee members, both internal and external to the NIDDK. He noted the logistics, explaining that questions will be captured in the chat window, which session moderators will monitor. Workshop documents—Framework for Breakout Sessions, Schematic of HD, and Schematic of PD—were provided before the meeting but can be accessed from the NIDDK [Meetings and Workshop](#) webpage.

Dr. Eric Wallace provided an overview of the theme of the workshop, highlighting additional questions the field should address. Since 2008, the incidence of home-based dialysis has increased steadily, which is primarily attributed to PD. The use of home HD because has remained unchanged over the past decades. Despite two inflection points in 2008 and 2012, the overall prevalence of home dialysis in the United States remains low among patients with end-stage renal disease (ESRD). Dr. Wallace pointed out the reason for the difference in incidence versus prevalence: most U.S. policies focus on starting and, to a lesser extent, maintaining patients on home-based dialysis. One question is whether the research and resources are adequate to retain pace with the increasing demands associated with maintenance.

In terms of Centers for Medicare & Medicaid Services (CMS) initiatives, the establishment of the ESRD Prospective Payment System (PPS) within the Medicare Improvement for Patients and Providers Act correlated with the increase in home dialysis. The 2019 Presidential Executive Order on Advancing Kidney Health for Americans encourages that 80 percent of ESRD patients have a kidney transplant or start home dialysis by 2025. Support of this level of growth requires a home dialysis system, and this workshop's planning committee developed schematics for home HD and PD depicting the necessary components for start and maintenance. For PD initiation, education for patients and providers (remote and in person), disparities in instruction, and adult learning approaches should be addressed. Regarding access, the field would need to address questions on the availability of trained surgeons and operators to place catheters properly, standards and best practices, technologies to prevent catheter malfunction, and CMS payment models for access surgeries.

Home initiation practices affect outcomes and prompt questions on a standard definition of urgent start, traditional training, assisted PD, and transitional care units. After initiation, the next concerns are complications from PD, including infections due to technique failure, especially within rural facilities; access to hospitals equipped to address procedural problems; patient burnout; and peritoneal membrane failure. Other questions remaining are related to ways to address encapsulating peritoneal sclerosis, transitioning from home to in-center dialysis, and monitoring patients remotely regarding technique failures.

Dr. Wallace concluded that any proposed increase in home dialysis should be viewed as a system so that training and research on all aspects of the system can be ensured. Much work is necessary to ensure that a massive shift to home therapies is possible, equitable, safe, and optimized for patients. The field owes it to patients to increase home dialysis research.

References

1. Lin E, Cheng XS, Chin KK, et al. Home dialysis in the prospective payment system era. *J Am Soc Nephrol.* 2017; 28 (10): 2993–3004.

- Wallace E, Fissell RB, Golper TA, et al. Catheter insertion and perioperative practices within the ISPD North American Research Consortium. *Peritoneal Dialysis International (PDI)*. 2016;36(4): 382–386.

SESSION 1: Patient Perspective

Patient Panel

Moderator: Janice Lea, M.D., Emory University

Panelists: Vanessa Evans, M.A., Fresenius Medical Care; Leigh-Ann Williams, M.P.H., M.S., American Association of Kidney Patients (AAKP) Ambassador; Mihi Wickramasinghe, AAKP Ambassador, Chaffee College

Dr. Janice Lea remarked on how having the patient’s perspective was the highlight of this innovative workshop. She invited the panelists to tell the stories of their personal home dialysis experiences, touching on what has succeeded and the challenges.

Home HD

Ms. Leigh-Ann Williams, who is 28 years old, started HD one month before earning her bachelor’s degree. This required lifestyle changes and affected her plans to travel as the international third vice president of her sorority. She began in-center dialysis 3 days a week—on Mondays, Wednesdays, and Fridays—and traveled to more than 19 clinics within 16 months of being on dialysis. This experience was unique in that many dialysis patients rarely leave their home clinics for therapy. When the opportunity for home HD was presented, along with the prospects of participating in activities challenging for dialysis patients (e.g., taking a cruise), Ms. Williams was on board, regardless of the education and training required. Because of the flexibility of performing home therapy 4 days a week for 3.5 hours each day, she has returned to college and earned two master’s degrees and also works full time.

Ms. Williams expressed her gratitude for this modality that enables evening sessions that work best with her lifestyle and activities. She is a member of several kidney-related organizations and participates in many related programs and initiatives, including the Kidney Health Initiative and the Patient and Family Partnership Council. As an ambassador for the AAKP and American Kidney Fund, she advocates for patients to (1) get involved in their own kidney care, (2) learn as much they can about this care, and (3) be willing to learn. After 5 years of being on dialysis, Ms. Williams indicated she is still learning about home HD and kidney care. She called attention to an online tool that helps the individual decide on the best treatment modality based on their circumstances. She is fortunate to have three family members trained to assist her as care partners: her mother, sister, and grandmother. Ms. Williams noted challenges that the home HD community could address, specifically SDoH and access to care.

Ms. Vanessa Evans, who has been a dialysis patient for 24 years, has been on home HD for 16 years. In her 8-year journey with in-center dialysis, she encountered very few discussions of home HD or PD. After hearing some conversation of home therapy, she searched online for further information and discovered the NxStage® HD machine (Fresenius Medical Care). Because of her fears about handling an emergency and addressing cannulation issues, Ms. Evans took 1.5 years to transition from in-center to home HD. In addition, she was not in favor of more frequent dialysis sessions and did not have a good understanding of why more was better.

Ms. Evans emphasized identifying resources and credits her in-center patient care technician (PCT) with encouraging and training her in the guided method of needle insertion. Within days of starting home HD, she was able to discontinue medication for blood pressure control and work full time with ease.

Ms. Evans leads the Fresenius Medical Care patient advocacy group and promotes home HD. She encouraged patient education, focusing on understanding the “why” and clinical benefits of the in-home modality. When patients take charge in their treatment, then the greatest shift to this modality likely will occur. Developing simpler ways for patients to safely dialyze at home, addressing access issues, and developing the related technologies will be critical.

Dr. Lea spoke on behalf of her patient, **Mr. Dana Clay**, who was unable to attend. Mr. Clay has been on home HD for more than 20 years, with the same arteriovenous fistula from the initial start.

Home PD

Ms. Mihi Wickramasinghe, who is 21 years old, has been on home PD for the past 4 years after resuming dialysis following a kidney transplant that her body rejected. Although Ms. Wickramasinghe has been successful with this treatment, of which the Peritoneal Equilibration Test is a measure of effectiveness, peritoneal membrane failure remains a major concern for her and other patients. She is an AAKP ambassador, works with the Renal Support Network, and attends support group meetings. From her experiences, home PD patients generally have concerns about adequate space to house the necessary materials and whether they will have the time and energy to continue this course of therapy.

Questions

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK

- In response to a question (in the chat) about travel (given that some of the new equipment options are not portable), Ms. Evans commented on the challenges of receiving treatment away from a local center and how that limited her family’s travel. An intake form was required, she was placed on a waiting list, and spent almost an entire day at the away center—a traumatic experience that prompted her to consider home therapy and aspects of portability.
- When asked about nighttime dialysis (in the chat), Ms. Wickramasinghe explained that nighttime home PD provided her the flexibility to attend college full time and in person during the day and continue schoolwork from home, sometimes while on dialysis. She added that she travels with her machine and supplies; her care partner, her mother, helps with acclimating to a new environment, thus making the trip enjoyable.
- Dr. Lea asked the home HD patients to comment on nighttime home HD, touching on any fears or anxieties. Ms. Williams, who dialyzes between 6:30 p.m. and 11:00 p.m., has no fears or anxieties of nocturnal HD (i.e., slower, longer treatment during sleep), but prefers keeping her dialysis and sleep times and those areas separate. Ms. Evans, who has performed solo, frequent, and nocturnal dialysis, finds that dialyzing five to six times weekly and sleeping away from the machine best suits her needs. She highlighted treatment options within a specific modality, the role of a care partner or team, and a patient’s growth in terms of family dynamics within dialysis over time. Mr. Erich Ditschman (National Kidney Foundation [NKF], in the chat) noted using a small HD machine (since 2008) at his bedside for nocturnal HD. He prefers it because it is longer and slower and does not interfere with his daytime activities, and because of his taping technique, he has never had a needle dislodge. Ms. Dawn Edwards (Rogovin Institute, in the chat) commented on having no fears of nocturnal home HD, which has enabled her to return to work and engage in more activities that she enjoys.
- Dr. Paul Kimmel (in the chat) asked for the patients’ perspectives on a key research question or policy issue that must be addressed. Ms. Evans suggested promoting peer-to-peer mentorship and

increasing awareness of the online resources (e.g., [Home Dialyzors United](#)). She also emphasized focusing on research tailored to the individual patient, addressing the effects of emergent situations, such as the coronavirus disease 2019 (COVID-19) pandemic, and identifying other measures of treatment efficacy beyond dialysis dose and system volume (i.e., Kt/V).

Ms. Wickramasinghe noted approaches to prevent PD complications—such as infections and membrane failure—as research areas to explore. Patients need answers to their questions about transitioning from HD to PD, regardless of the setting.

- When asked (in the chat) about frequent sessions and home HD burnout, Ms. Evans explained that dialysis has been incorporated into her life as a normal routine, acknowledging that days of not wanting to dialyze can occur. She encourages making use of respite care for patients and care partners if they are feeling overwhelmed, speaking with a social worker, and learning all you can about your treatment and care.
- In response to the mention (in the chat) of using the buttonhole technique for cannulation, the patient consultants noted the effectiveness of this approach, and some had used this technique when starting HD.

SESSION 2: Process and Lessons Learned

Overview of the Current Process for Home Dialysis: Evaluation, Counseling, and Implementation

Prayus Tailor, M.D., Nephrology Associates, P.A., Delaware

Dr. Prayus Tailor explained that the first step in counseling and evaluation is discussing kidney failure with the patient. The Renal Physicians Association (RPA) developed a shared decision-making guideline consisting of 10 recommendations to facilitate these discussions. The recommendations emphasize explaining to patients why they have kidney disease and the prognosis; informing them about treatment options, including conservative therapy; and addressing conflict resolution regarding a time-limited trial of dialysis when appropriate. The initial discussion with patients can occur in two settings: (1) in an office, with a controlled start to dialysis usually following diagnosis of stage 4 chronic kidney disease (CKD) or (2) in a hospital with a crash-dialysis start in response to acute kidney injury (AKI) or progressive CKD. The aim is to adjust to these settings with the necessary staff and available resources and tools (e.g., Method to Assess Treatment Choices for Home Dialysis [MATCH-D] or My Life, My Dialysis Choice). Patients seen in the office initiate treatment with in-center HD or PD, or home HD, whereas patients in the hospital setting begin on HD or PD. Multiple ways and programs to relay education can be used for clinician-patient discussions in office, but conversations in the hospital are limited to one-on-one discussions at the bedside. The overall goal is to respect patient autonomy. Each home dialysis modality (HD or PD) presents with specific medical indications and psychosocial determinants (e.g., full-time work, traveling): the aim is to minimize potential patient barriers, of which homelessness and uncontrolled anxiety cross-cut modalities.

Regarding implementation of home dialysis, a team consisting of physicians (e.g., nephrologists), care navigators, educators; and health systems, including the surgical practice and home dialysis unit, are engaged and working in concert. The patients and their families are at the center, and care coordination is critical. Dr. Tailor emphasized that care navigators within Nephrology Associates, Delaware assist in simplifying the care process for physicians and patients by providing patient education, scheduling surgical evaluation, and coordinating with the home dialysis unit. For example, the most efficient flow path for a stage 4 CKD patient begins with rigorous predialysis education followed by modality selection and the associated surgery. The next steps will be home unit coordination, access site creation and maturation, and training. Dr. Tailor called attention to a review article published in the October 2020 issue of *Kidney360* describing steps involved in evaluation and selection of late-presenting end-stage kidney disease urgent-start PD that would apply to urgent-start HD. He highlighted the

transitional care unit (TCU) implemented in Nephrology Associates, Delaware consisting of a 4-week curriculum for patients, enabling well-informed decision-making about treatment choices.

References

1. Rajora N, Shastri S, Pirwani G, et al. How to build a successful urgent-start peritoneal dialysis program. *Kidney360*. 2020;1:1165–1177.
2. Lockridge R, Weinhand E, Kraus M, et al. A systematic approach to promoting home hemodialysis during end stage kidney disease. *Kidney360*. 2020;1:993–1001.

Questions

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- A participant (in the chat) remarked that the biggest barrier is trying to convince patients that they can take care of themselves and that their lives are not over because they are on dialysis. Dr. Taylor agreed that patients often are not ready to decide about dialysis, noting that with the TCU approach, patients are started on treatment, feel better, and are empowered to take on some of the responsibility of their care. Time and support are needed to enable such decisions, which is often unrecognized in the renal physician community, and a change in work models could help facilitate this.
- A participant (American Nephrology Nurses Association, in the chat) commented that education can be complicated. For example, the veteran population is not always ready to hear about these options, and when a statement is made that “you do not need dialysis right now,” it is hard to convince them otherwise.

CMS: What Are Gaps, and What Has Been Learned from Technical Expert Panels (TEPs)?

Jesse Roach, M.D., CMS

Dr. Jessie Roach discussed gaps in home dialysis and the lessons learned from the TEPs. The CMS contracted with University of Michigan’s Kidney, Epidemiology and Cost Center (UM-KECC) to develop a measure of home dialysis uptake applicable across CMS programs (e.g., Payment Program or Five-Star Quality Rating System). Of note is that the NIDDK partially funds UM-KECC projects. This CMS-UM-KECC TEP—composed of clinicians, experts from academia and industry, and patients—convened in virtual meetings and discussed gaps in home dialysis measures. Dr. Roach elaborated on the most common measurement gaps identified by the TEP members, noting potential solutions and next steps.

- ***Effective pre-dialysis education:*** Measuring the number of patients starting on a home modality would be a reasonable surrogate for evaluating whether the dialysis type aligns with the patient’s goals for care.
- ***Peer-reviewed education:*** Developing an objective, fact-based educational program that is transparent, is free from bias, and presents positives and negatives of each modality could help standardize the decision support process.
- ***Measures of complications related to home dialysis:*** Measuring peritonitis would be complementary to the National Healthcare Safety Network (commonly called NHSN) measure of HD bloodstream infections.

- **Measures of retention of home dialysis patients in their modality:** Considering the number of months on home dialysis would be one place to start.
- **Measure of home patients similar to the CMS In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH-CAHPS):** A home dialysis patient-specific survey similar to ICH-CAHPS is being validated in the renal community, but will require input from patients.
- **Provider-level metric for home dialysis that switches in the first year:** Aligning metrics between dialysis facilities and providers will enable better coordination in reaching goals.
- **Measures of changes of home dialysis after the first year:** Although it happens to a lesser extent, conversions from home to in-center dialysis potentially can occur after the first year.

References

1. UM-KECC. <https://kecc.sph.umich.edu>
2. Technical Expert Panel Charter. Effective Availability and Utilization of Home Dialysis Modalities. <https://www.cms.gov/files/document/effective-availability-and-utilization-home-dialysis-modalities-tep-charter.pdf>

Questions

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- Dr. Stephen Ash (in the chat) made several key points, noting that one major benefit of home HD is that treatments can be done more frequently. This improves patient health by better treating the uremia. CMS guidelines routinely pay for only three treatments per week in the home unless concomitant diseases like congestive heart failure can be identified. For patients on four to five treatments per week, HD requires the use of more disposable materials and increased effort from patients and their supporters. He asked whether the CMS is considering paying for all the dialysis per week that the patient performs. Dr. Roach could not comment on payment decisions in progress at the CMS. He clarified that the CMS covers medically necessary treatments and explained that local Medicare Administrative Contractors in a specific geographical region decide coverage determinations. Efforts are ongoing at the CMS to modify current practices to enable more patients to adopt home dialysis.
- Dr. Brigitte Schiller (in the chat) noted that Dr. Matthew B. Rivara's (University of Washington) home patient experience survey ([Development and Content Validity of a Patient-Reported Experience Measure for Home Dialysis](#)) would be applicable to fill the gap regarding lack of an ICH-CAHPS measure for home dialysis.
- Dr. Ash emphasized that increasing the profitability of home dialysis for providers likely would spur new technologies and promote this modality among patients, especially if payment structures support more frequent weekly dialysis sessions. From a patient's perspective, Ms. Evans, as an 8-year home HD patient whose health has benefitted from more frequent dialysis, highlighted the practicality of having a payment structure that extends beyond dialysis three times per week.
- When asked by a participant (in the chat) whether the CMS is seeking to redefine quality metrics for home dialysis—such as patient-centered outcomes, peritonitis, technique failure, or quality of life (QoL)—Dr. Roach clarified that the goal of the TEP is to develop measures that appropriately reflect and are specific to home dialysis.

- In response to a question from Dr. Abbott about whether the CMS is seeking additional evidence indicating the benefits of frequent dialysis to inform decisions on payment, Dr. Roach noted that it remains an issue of expenditures and costs and keeping the budget neutral when making changes to CMS programs.
- A participant (in the chat) commented on how the composite Kt/V metric disincentivizes PD and is difficult to achieve among PD more so than HD patients. Dr. Roach pointed out that the CMS continues to balance the legal requirements for measuring dialysis adequacy with patient outcomes and improvements in PD care. Evaluating any unintended consequences is ongoing.

SESSION 3: Education and Training

Patients and Caregivers

Janice Lea, M.D., Emory University

Dr. Lea presented on the education and training needed to support successful home dialysis for patients and caregivers and began by summarizing some of the published literature on this topic. In 2019, Manera *et al.* reported on outcomes important to PD patients and their caregivers. When asked by focus groups what was important to them, the study participants responded that low infection rates, improved survival rates, reduced fatigue, and flexibility with time were high on their list. Other studies on patient priorities and perspectives with dialysis revealed that QoL—as it relates to social interactions, work, family, and the comfort of feeling better—mattered most to patients. The priorities of receiving a transplant, length of life, independence, and flexibility also ranked high, but did not include parameters that clinicians measure (e.g., Kt/V). A 2016 report (Dalrehus *et al.*) on empowering patients about choices for renal replacement therapy revealed that educating patients on home modalities resulted in 95 percent choosing home PD and 47 percent selecting in-center HD. In 2010, Schiller *et al.* reported that the majority of health care professionals (e.g., clinicians, nurses), if given the choice, would select a home modality for patients.

Systematic barriers, particularly education on all levels (e.g., patients, physicians, dialysis staff) continue to be major contributors to the gap in home modality choice and patient uptake. Dr. Lea focused her discussion on the patient’s perspective and efforts at Emory University to increase and enhance patient education. In 2017, Subramanian *et al.* reported that when asked about coping with kidney disease and what presents as most bothersome, most patients cited time spent on dialysis, dietary restrictions, the inability to travel, lifelong incurable and fatal aspects, lack of control, and limited treatment options. Dr. Lea, who is the recipient of a Patient-Centered Outcomes Research Institute (PCORI) Peer Mentorship grant, used this information as a framework for her study titled “Enhanced Patient Engagement to Improve Patient-Centered Outcomes Among CKD.” Emory University partnered with AAKP and Kaiser Permanente Georgia to conduct this patient-centered study, which is still active. This study engages patient advocates for home dialysis and kidney transplant to mentor other patients and help improve their coping skills. Patients are matched based on similar experiences and characteristics. The goal is to reach unengaged patients who have not taken control of their dialysis experience. The overall patient engagement strategies are to (1) increase patient advocate and ambassador mentors to provide education and (2) increase patient-centered research for home dialysis.

Dr. Lea touched on the benefits of telehealth to home dialysis regarding early diagnosis and treatment, routine remote monitoring, a decrease in emergency room visits and hospitalizations, and an increase in patient satisfaction and comfort. In closing, she noted key points for success in home dialysis: patient education and engagement, peer mentorship, caregiver support, and telemedicine.

References

1. Manera KE, Johnson DW, Craig JC, et al. Patient and caregiver priorities for outcomes in peritoneal dialysis: multinational nominal group technique study. *Clin J Am Soc Nephrol.* 2019;14(1):74–83.
2. Subramanian L, Quinn M, Zhao J, Lachance L, Zee J, Tentori F. Coping with kidney disease - qualitative findings from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) study. *BMC Nephrol.* 2017;18(1):119–129.

Clinicians

Michael Rocco, M.D., M.S.C.E., Wake Forest School of Medicine

Dr. Michael Rocco described home dialysis education and training for clinicians. He reviewed the renal fellowship training programs and home dialysis therapies and discussed opportunities to provide training and mentorship for clinicians in practice, particularly within Project ECHO (Extension for Community Healthcare Outcome). A 2010 survey of the training level and competence in care of dialysis and transplant patients among 133 respondents who had completed nephrology fellowship training revealed that although more than 80% of trainees reported being well trained and competent in providing in-center hemodialysis, less than 60% believed that they were well-trained in peritoneal dialysis and less than 20% believed that they were well trained and competent for home hemodialysis, with more than 60% indicating they received little or no training in home HD. The Accreditation Council for Graduate Medical Education requirements for competency in dialytic therapies do not mention home HD in the core curriculum and, unlike in renal transplant, fellows have no minimum number of PD or home HD patients they are required to follow during their training. The requirements for a home dialysis training nurse consist of 12 months of work experience as a registered nurse, with 3 of those months focused on PD or home HD patients. No specific education requirements of other dialysis staff in PD or home HD exist, nor is there any mention of these modalities in the content for board certification for renal nutrition specialists. Dr. Rocco called attention to the variability in fellowship training programs in home dialysis regarding clinical rotations and training. A more ideal arrangement, he proposed, would be an intensive month-long training in PD and home HD with ongoing continuity within a home dialysis clinic.

In terms of mentorship for providers in practice, Dr. Rocco detailed a 5-point mentorship plan consisting of (1) establishing a home dialysis expert panel, (2) training staff in videoconference teaching, (3) identifying interested dialysis providers, (4) providing mechanisms to allow submission of de-identified cases, and (5) conducting weekly education and case presentation sessions. Project ECHO, developed at the University of New Mexico Health Sciences Center, is one such design to explore executing this plan. ECHO, a distance health education model, uses videoconferencing technology to connect care providers across multiple geographical settings and areas of expertise. After completing a home dialysis needs assessment and establishing a forum composed of high-performing home dialysis centers and a multidisciplinary team, Dr. Rocco envisions ECHO home dialysis projects for which potential outcome measures would include incidence rate, knowledge of home dialysis modalities, impact of education programs, and information on attrition rates and provider and patient satisfaction level, as well as self-efficacy.

Dr. Rocco informed workshop participants that the National Kidney Foundation has partnered with Networks 16 and 19 to sponsor a series of mentorship virtual meetings using the Project ECHO format. The meetings, which occur every 2 weeks, consist of a 60-minute case-based discussion for training members of a health care team on home dialysis, followed by 20 minutes for didactic curriculum. He concluded that training for clinicians in home dialysis therapies is inadequate. Fellowship training programs need to be revamped, and clinicians need both ongoing and refresher training courses and mentorship from experienced home dialysis clinicians.

References

1. Berns JS. A survey-based evaluation of self-perceived competency after nephrology fellowship training. *CJASN* March 2010;5(3) 490-496.
2. Project ECHO. <https://hsc.unm.edu/echo/>

Questions

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- Dr. Ash (in the chat) asked about ways to increase training in nephrology interventional techniques (e.g., fistula or graft access devices) among renal fellows. Dr. Rocco noted that these techniques should be included in a nephrology fellowship training program, of which some do provide fellows with the opportunity of rotating through an interventional nephrology access center. Dr. Ash remarked on the value of point-of-care ultrasounds to nephrologists to evaluate fistulas or grafts in their patients.

SESSION 4: Social Determinants of Health

Adam Wilk, Ph.D., Emory University

Dr. Adam Wilk explained that the CDC defines SDoH as conditions in the places where people live, learn, work, and play that affect a wide range of health and QoL risks and outcomes. Healthy People 2030 (the U.S. national blueprint for public health goals) identifies five key SDoH domains—economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context—all of which cross-cut home dialysis. Several studies have demonstrated the connections between SDoH and kidney disease. In 2012, Patzer and McClellan published a multilevel framework of health disparities in patients with kidney disease. The authors emphasized that SDoH extend beyond the nephrology perspective to fetal and childhood development to adulthood, touching on all phases of kidney disease progression.

SDoH involve a persistent daily exposure to a number of factors for extended periods of time and throughout the lifetime. Dr. Wilk described a timeline of ideal home dialysis care consisting of pre-kidney failure care, initiating kidney failure treatment care, and maintenance, all leading to specific patient outcomes. He elaborated on how SDoH affect all phases of this timeline. Patients with sufficient access to care and health insurance would be more likely to have adequate pre-kidney care, which would involve building a relationship with a nephrologist to potentially slow CKD progression and increasing access to home dialysis. Conversely, patients with limited social support or who have experienced victimization by discrimination may be distrustful of health care providers, which would result in less communication about treatment choices leading to disparities in home dialysis. SDoH related to home, work, or environment can determine the home dialysis technologies suitable for a patient, but access will depend on local programs.

Several levels of U.S.-based evidence link SDoH to home dialysis use based on common factors (e.g., education, employment, access to pre-ESRD care). A subset of these studies seeks to determine the role of racial and ethnic influences. Evidence associating SDoH with treatment outcomes in U.S.-based home dialysis is limited. A few international studies have filled the gap in U.S. studies in terms of educational attainment and health literacy, and all link to improved technique survival in home PD. Dr. Wilk pointed out that the CMS 2728 Medical Evidence Reporting Form data included in the U.S. Renal Data System (USRDS), which many researchers use to study national trends in home dialysis, do not capture data on patient education or health literacy levels.

To conclude, Dr. Wilk highlighted notable gaps in SDoH and home dialysis regarding the maintenance phase of care; the household, community, system, or policy factors; long-term exposures; home HD relative to PD; and interventions. These gaps present widespread opportunity for future studies.

References

1. Patzer RE, McClellan WM. Influence of race, ethnicity, and socioeconomic status on kidney disease. *Nat Rev Nephrol.* 2012;8(9):533–541.

Questions

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

Questions were deferred until the Breakout sessions.

BREAKOUT DISCUSSIONS: Patient Engagement, Education and Training, and SDoH

Participants attended one of three breakout groups. A guiding framework was provided to focus the discussions.

Maintaining Patient Engagement in Home Dialysis

Group Leaders: Janice Lea, M.D., Emory University; Vanessa Evans, M.A., Patient, Fresenius Medical Care

Optimizing Education and Training of Patients, Caregivers, and Clinicians

Group Leader: Christopher Chan, M.D., University of Toronto

Impact of Social Determinants of Health on Home Dialysis Utilization and Success

Group Leaders: Adam Wilk, Ph.D., Emory University; Sonya Brady, Ph.D., University of Minnesota, School of Public Health

Reports from Breakout Sessions

Moderators: Shannon Givens-Bradley, M.P.H., NIDDK; Kevin Abbott, M.D., M.P.H., NIDDK

Dr. Abbott invited the breakout group leaders to report the results of their discussions, touching on gaps, challenges, and barriers.

Patient Engagement

Dr. Lea reported that the group discussed ways to educate patients so they can stay engaged in home dialysis, which they summarized in three areas framed as questions. First, how should patients be educated and what are the best ways to educate them? Second, what is the appropriate time course and when should the education begin? Third, what should patients be told and why, and how should messages be disseminated?

In terms of ways to educate patients, discussions focused on the role of peer mentorship. Workshop patient consultants shared their stories and experiences with dialysis staff, including the PCTs who were instrumental in educating them. Participants highlighted the variability of practice among physicians and medical providers and overarchingly emphasized peer mentorship as one of the leading areas that could reliably and broadly be implemented to reach patients. One patient who had been on dialysis for 20 years remarked how peer mentorship could have benefited his long journey and comfort level.

Regarding the time course, the group discussed preparing patients properly along their disease course as early as stage 3 CKD, rather than waiting until patients progress to advanced CKD on dialysis. Several key points

emerged from the discussion. People generally will not be tuned to listening and engaging in their care when they crash-start on dialysis. Another layer of education for the hospital and its infrastructure would need to be considered. Although the majority of patients would have seen their health care providers years before starting dialysis, time to prepare properly remains inadequate because they were in denial, did not have it emphasized by a clinician that they would eventually require dialysis, or they were informed of their diagnosis in the later stages of CKD. This, the group discussed, speaks to the need for education of clinicians and medical providers. It also was noted that medical and nursing school curricula should include information on the life journey of patients with CKD and the importance of home therapies.

To address what and why, Dr. Lea explained that the workshop patient consultants emphasized having educational materials that inform patients of their overall health status and guide them through the life trajectory and transition (PD to HD) between modalities. Such materials will better prepare dialysis patients to understand that if one therapy fails, they should be prepared consider another option.

Education and Training

Dr. Christopher Chan summarized the group's discussion, noting that the current status quo, they surmised, is not ideal. The group recognized that the current system for education and training is tailored to in-center dialysis, with minimum awareness about home dialysis. Participants envision a "home-preferred" philosophy, with home dialysis as a core competency for nephrologists, nurses, patients, and care partners. Within the entire ecosystem of home dialysis, health care providers need to be mindful and educated about how to start, maintain, and transition patients on dialysis, all in the context that other modifiers (e.g., SDoH) play a role. The group further discussed that with such a core competency, national standards and regional specialization (e.g., regional hubs or call centers) might be potential models of care, given the limited number of available patients to allow the appropriate training and exposure needed. Dr. Chan emphasized that the current cohort of home dialysis patients is an important but scarce resource. The best approach to learning about home dialysis is through exposure to it and then education. Partnering with national entities would be critical to provide more allies to this cause.

Regarding training of patients and care partners, the group discussed individualized training that is iterative, is inclusive, and encompasses both the theory and the mechanics of dialysis, extending beyond the machine alone. This level of understanding will enable patients to better maintain their dialysis techniques. Dr. Chan conveyed that the group emphasized early CKD education and that it be supportive. They agreed that education also has to be "experiential" because different patients and care partners may require different types of support. Participants discussed the difference in care partners versus caregivers, which could be primary or ancillary with assisted home dialysis.

The group next discussed that training of clinicians is critical and that home dialysis should be viewed as a team effort with a strong focus on educating the whole home dialysis ecosystem, thus completing the circle of care. Again, viewing home dialysis as a core competency of nephrology would suggest that a minimum requirement of certification may be an important step to mandate this mode of teaching and education for all associated team members. Some participants recognized that human resources professionals are critical elements of an education program, but with a scarcity of these highly trained individuals, expanding to other ways of teaching and educating technicians, nephrologists, and nurses would be necessary. Discussions also touched on the potential of novel technology as a supplement to training, including virtual technology, telehealth experiential learning, and/or artificial intelligence.

Last, the group addressed an ongoing controversial issue regarding the economic pressure, peer pressure, and work culture of an in-center HD unit. Dr. Chan explained that they viewed this as a significant barrier to developing a preferred philosophy of care. The group discussed funding challenges and profit versus potential losses, especially in the initial phase of growing a home dialysis patient critical mass.

SDoH

Dr. Wilk reported that the group discussed and further developed a multilevel model of the SDoH of optimal home dialysis care and health outcomes he and co-group leader Dr. Sonya Brady populated before the workshop. The group primarily focused on factors beyond the individual level to the societal, political, communal, institutional, and interpersonal levels. To address society and policy, Dr. Wilk first emphasized that not all SDoH are amenable to interventions, and those that are not potentially can be addressed with policy. The group discussed housing, specifically what constitutes a home environment in this context, telemedicine access, and personalized care, including its prioritization as a factor that could best be addressed at the policy level.

At the community level, geographic access (meeting people where they are) and support for individuals with unstable housing and those in skilled nursing facilities (SNFs) was highlighted. At the institutional level (e.g., dialysis facilities), the group emphasized standard assessments of SDoH and translating those into personalized care, the content of education programs for patients and care partners, and the use and implementation of telemedicine. In terms of the interpersonal level, the group discussed education programs and family needs.

Group Discussion

Moderator: Kevin Abbott, M.D., NIDDK

- A participant cited a need for policy changes for patients who crash-start dialysis and continue care at a rehabilitation center or SNF. Choosing the most optimal dialysis modality, such as PD, in these settings would be challenging. Dr. Wallace commented that the issue extends beyond policy to the number of patients actually receiving in-house dialysis at SNFs such that it would be self-sustaining. It becomes a cost issue for SNFs or similar facilities to retrain staff in a technique not used routinely until the population needing these services increases. Also, the issue of inducement (i.e., paying to receive patients) plays a significant role. Dr. Rachel B. Fissell (Vanderbilt University Medical Center) explained that one rehabilitation hospital in the Nashville area resolved this issue by having the highly trained dialysis facility staff from Fresenius Medical Care available around the clock. The training for that hospital's nurses is minimal. She commented that incentivizing PD for the large dialysis organizations (LDOs) could help solve some of the issues with training in SNFs.
- Dr. Abbott asked whether sufficient evidence to support the shift in dialysis to the SNFs and the role of LDOs is available and, if not, he requested input on what research or additional information would be needed. Dr. Roach commented that changes to CMS programs do warrant evidence, and additional studies sponsored by the NIH would be helpful. Dr. Abbott added that the USRDS database and potentially others could be interrogated to generate testable hypotheses on this topic.
- Dr. Ash explained that rehabilitation hospitals can accept patients and have separate billing for in-house dialysis, enabling LDOs to facilitate HD or PD at those locations. In-house dialysis at a SNF would be more complicated. The cost of supporting such a procedure is connected to the daily bed charges, and the mortality rates for dialysis patients tend to be high because of the overall health status of patients. Dr. Abbott pointed out that USRDS data revealed that the leading cause of hospitalizations among patients who survive 3 months after starting dialysis was being transferred to a rehabilitation center, which then becomes their home.

- Dr. Schiller moved the discussion to mentoring for patients and asked workshop patient consultants to comment on their successes and/or the type of mentorship program they would need. Ms. Evans noted leveraging the existing resources and increasing awareness of the various dialysis-related communities (e.g., Home Dialysis Central) and those associated with LDOs, similar to the 75-member advocate group she manages, which is composed of patient representatives from all LDOs. She credits her PCT and other in-center staff with helping her cross the dialysis hurdles and emphasized equipping those staff with the necessary knowledge and resources on how best to speak to patients. Social media is one well-utilized outlet among patients. Dr. Lea added that virtual meetings—within the Emory University peer mentorship PCORI project she described earlier—made necessary because of the COVID-19 pandemic have been successful. In-center dialysis patients were informed of the project by the study team during their in-person visits, were connected to mentors, and continued virtual interactions. Ms. Cecilia Santana (Rogosin Institute) remarked on her experience and positive feedback as a mentor with her organization and with Dr. Lea’s PCORI peer-mentorship study. She emphasized that patients gain confidence and are empowered by their mentors who have experienced dialysis and all that it entails, including transitioning treatment modalities. Dr. Abbott commented that the NIDDK has funded clinical trials with patient navigators who may or may not have been mentors. The best-qualified navigators would be dialysis-experienced mentors, but he was not sure if that would be scalable to support studies.
- Dr. Abbott asked the breakout session group leaders to submit testable ideas or projects they discussed. He asked for input on bridging the gap that telemedicine potentially could present between patients who may not have internet access. Dr. Wallace, who is an expert in telemedicine and home dialysis, explained that grant funding initially allowed him to provide telehealth services to his patients who did not have the necessary equipment at home. Patients traveled to a local, designated location. UAB Medicine has since partnered with Alabama county health departments to expand these services to a wider group of patients, but operational challenges remain. He suggested defining telehealth clearly as an in-home service or one that is external to in-office service or clinics because the rules of inducement would prohibit providing devices linked to the internet for other than the intended use. Dr. Wallace added that telehealth used incorrectly could widen a health disparity.
- Dr. Schiller asked whether use of technology in health care delivery would alleviate the issues with inducement and whether home dialysis training can occur via telemedicine. Ms. Evans commented that patients could benefit from virtual training on the basics of dialysis and noted use of virtual reality technology as an additional approach to explore. Dr. Abbott called attention to the many clinical trials testing mobile technologies and devices to improve medication use and ability, in which inducement has not been an issue. This could be a model to generate telemedicine and home dialysis evidence.
- Dr. Ash noted a training resource: newer home dialysis machines equipped with sophisticated video programs and step-by-step instructions for assembly and use. Because patients can be trained on visually directed machines faster than with the traditional models, he suggested this as an area to investigate further. Dr. Lea suggested using the virtual approach for retrainings and continuing education in the home units.
- Dr. Wallace proposed an experimental design for a home dialysis study: First, randomize patients with a diagnosis of peritonitis to either a standard dialysis machine or a machine with education modules; then conduct virtual training for 1 week or provide educational videos once a week. Evaluate the outcomes.

- Dr. Abbott moved the discussion to social media hesitancy in the medical community and fear of liability. He asked Ms. Evans for suggestions that could help health care providers and institutions feel more comfortable using these platforms. Ms. Evans explained that most regulated environments in the medical community and their associated groups have a social media presence that can be used to reach and inform patients. She suggested embracing social media as a platform most dialysis patients frequent for information while managing a chronic illness.
- Dr. Abbott next asked for comments on patient selection for home dialysis. Dr. Fissell noted that at her hospital, PD rather than in-center HD is a conscious choice for patients in hospice. She pointed out that flexibility and shifting modalities remain important concepts to consider. Dr. Lea explained that the major utility of PD in a SNF is when the patient with an acute illness is already using that modality and is expected to return home.

Summary of Day 1, Charge for Day 2

Kevin Abbott, M.D., NIDDK; Robert Star, M.D., NIDDK

Dr. Abbott summarized the key points that emerged from Day 1 of the workshop framed by the breakout session themes.

Patient Engagement

- Meet the patient where they are.
- Home dialysis use is at 10 to 15 percent in the United States, and engaging self-sufficient patients would be one place to start to increase this uptake.
- Patients pair well with mentors who have had the dialysis experience and/or have had a kidney transplant.
- Tools and resources for communicating with patients are underutilized.
- PD remains more utilized than HD, but has a limited life cycle.
- Transitioning modalities is common, and patients should be alerted to and educated about this process.
- Patients are interested in knowing about the theory and adequacy of dialysis.

Education and Training

- The status quo is inadequate to train the current and next generations of health care providers.
- Detailed training is needed across the whole spectrum, including caregivers, providers, physicians, nurses, and dieticians.

SDoH

- The extended SDoH schematic—including factors beyond the individual level—provides an in-depth perspective and identifies areas that the NIH could support in research studies.
- The SDoH themes cross-cut patient engagement and suggest that technologies potentially could address care gaps for patients.

Day 1 Recess

Dr. Abbott explained the logistics for the following day and reviewed the remainder of the meeting agenda. The meeting was recessed at 2:57 p.m.

THURSDAY, JUNE 3, 2021

SESSION 5: Posters

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK

The IM-HOME Study: Identifying Major Home Dialysis Barriers

Yuvaram Reddy, M.D., MBSS, M.P.H., Massachusetts General Hospital

Dr. Yuvaram Reddy outlined an upcoming project to analyze barriers to utilizing home dialysis. The U.S. goal is for 80 percent of new ESRD patients to begin dialysis or receive a transplant by 2025, but less than 13 percent of patients start dialysis at home and less than 50 percent of those stay on home dialysis after 4 years. Specific strategies are needed to improve these rates—existing strategies are effective in their local contexts, but their effectiveness nationally is unclear, as is whether they would meet the needs of other health systems, patients, or providers. Local strategies are difficult to implement in other settings without a sense of which components are the most effective. Implementation science frameworks—such as the Consolidated Framework for Implementation Research (CFIR)—may help build strategies that are more effective and acceptable. To use the CFIR, identified barriers are classified as inner-setting characteristics, outer-setting characteristics, intervention characteristics, and characteristics of individuals. This analysis allows users to confirm that they have missed no components of a strategy.

Most implementation science frameworks require a detailed understanding of both patient-level and provider-level barriers. The objective of this mixed-methods study are to (1) identify barriers from the patient and provider perspectives, (2) assess how perspectives of barriers differ nationally and locally, and (3) determine what components might be acceptable and feasible to implement locally. The study will integrate both qualitative and quantitative data by distributing a survey to patients and providers nationally, and interviewing patients and providers across two health systems to determine how local perspectives differ. Prior to the surveys, an advisory board will be convened to incorporate the perspectives of dialysis organizations, health care systems, kidney societies, policy experts, private practitioners, and veterans. The board will meet quarterly to provide input on study design, preliminary findings, and study conduct.

Regarding the survey method, members of the advisory board will provide lists of barriers, which will be compiled into a list of common patient and provider barriers. Patients and providers will rank their top barriers in the survey, and the results of the survey will identify strategies that can be targeted using the CFIR. When those barriers and potential strategies have been defined, interviews will be conducted at local health care systems in Philadelphia to determine if the national list of barriers differs from the local list and whether the strategies identified are acceptable and feasible to local stakeholders.

In conclusion, Dr. Reddy anticipated receiving a comprehensive understanding of the potential feasibility of strategies and the barriers from the national and local perspectives. For the next steps, he projected that the study would leverage implementation science principles to develop a comprehensive understanding of barriers and that the data would be used to develop, pilot, and implement novel strategies to improve home dialysis uptake for patients with kidney failure.

Discussion

- Dr. Schiller asked whether the study would adjust for the differences in the current rates of home dialysis in different areas of the country. Dr. Reddy explained that surveys will be anonymous, but providers will be asked to list their experience with home dialysis and percentage of patients who use home dialysis to assess the foundational level of home dialysis comfort and uptake.
- A participant asked about strategies for distinguishing between peritoneal and home HD. Dr. Reddy explained that the study currently does not separate those modalities, but the question must be considered further. Many patients will not have used home dialysis previously, and one barrier may be that they did not know it was an option.

- A participant asked whether the study would adjust for patients' baseline knowledge of home modalities and the resulting effect on perception of barriers or for any demographic factors. Dr. Reddy commented that adjusting for these factors would depend on the purpose of the study. Although SDoH are part of the complete spectrum of barriers, his team is looking for the most actionable barriers, and social determinants of health are difficult to address.
- Dr. Wallace pointed out that physicians often act as barriers and survey results would be skewed by who responds. He emphasized the need to control for the fact that those who are identifying the barriers have a vested interest. Dr. Reddy acknowledged the problem of response bias but noted that interviews should help provide more nuanced information. He emphasized that future studies beyond those developed for this study will need to include an on-the-ground component to identify feasible strategies.
- Dr. Schiller suggested identifying locations more representative of the United States, emphasizing that medicine is local, and that the scalability of national programs can become a barrier.

References

1. Damschroder, L.J., et al. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*, 2009. 4:50.
2. Tabak, RG, et al. Bridging research and practice: models for dissemination and implementation research. *Am J Prev Med*, 2012. 43(3): 337–50.

Incidence of COVID-19 Infection in Patients Performing Home Dialysis Versus Patients Undergoing In-Facility Hemodialysis

Eric Weinhandl, Ph.D., M.S., Hennepin Healthcare Research Institute

Dr. Eric Weinhandl presented a USRDS assessment of COVID-19 complications in home dialysis versus in-facility dialysis to determine whether home dialysis is protective against respiratory infections by virtue of its setting. The assessment showed a strong evidence of excess mortality for dialysis-dependent patients during the first three quarters of 2020. Although mortality rates decreased through the summer of 2020, deviance between expected and observed mortality persisted.

When considering the dialytic modality, PD showed a 64 to 68 percent lower risk of COVID-19 hospitalization during the second quarter of 2020. This could be because 99 percent of PD occurs at home, whereas more than 97 percent of HD occurs in a facility. This difference could be real, error, or confounding, and whether it occurs with home HD is unclear. The ascertainment of infection also is differential. Dr. Wallace commented that the risk of severe COVID-19 might be lower with fewer comorbidities, and sealed nursing facilities might have carried infections into dialysis facilities. Overall, the mechanisms of protection remain unknown. Whether home dialysis is a factor in mortality is multifactorial, but at home, patients are not exposed to a dialysis facility, public or medical transportation, and perhaps a monthly clinical visit.

This analysis was conducted by analyzing Medicare Parts A and B claims accrued during 2020. From epidemiological week 12 (March 15) through week 37 (September 6), patients with a Medicare-covered outpatient dialysis treatment during the preceding 7 days were identified. Patients were stratified into cohorts for in-center HD, home HD, and PD. Patients with in-center HD with residency in a skilled nursing facility during the 28 days preceding the epidemiologic week were excluded, which eliminates skilled nursing facility exposure as a factor. During each week, the incidence of COVID-19 infection and hospitalization was estimated using Medicare claims. Estimated adjusted odds ratios of outcomes during

epidemiological weeks 12 through 22 and weeks 23 through 33 were adjusted for age, sex, race and ethnicity, diabetes, heart failure, and state of dialysis.

Clear differences were shown between home dialysis modalities and the in-facility group; rates for the two home modalities were similar. Home modalities showed a 35 to 45 percent lower risk of COVID-19 infection. When the Medicare group of kidney transplant patients was assessed, hazard ratios were slightly more modest but remained protective. However, exposure to skilled nursing facilities was a major risk factor for COVID-19 infection and hospitalization.

Dr. Weinhandl concluded that home dialytic modalities are associated with lower incidence of COVID-19, but home HD rates and PD rates were similar. Additionally, the relative risks of home dialysis and kidney transplant were similar. One broader conclusion that can be drawn from this analysis is that although COVID-19 will pass, a return to previous population-level behaviors will increase upper respiratory infections and influenza. Providers offering counseling to people who are considering whether to dialyze at home could tell patients that home dialysis will protect them from contracting respiratory infections, particularly during winter; that some studies suggest that home dialysis could lower the risk of contracting respiratory infections, but the risk of bias is high; or that home dialysis offers benefits and risks, including risks of peritonitis with peritoneal dialysis and serious bloodstream infections with home HD. Dr. Weinhandl emphasized that the data are provocative and suggest that home dialysis affects aerosol-based conditions generally.

Discussion

- A participant pointed out that many of his patients with COVID-19 were from skilled nursing facilities, which presents questions of recurrence and relapse for dialysis patients who have increased exposure to both patients and staff in a HD unit. Dr. Weinhandl commented that assessing recurrent infections could extend this analysis, but using claims data would require analyzing a certain period of time without an infection, then noting when the infection returns.
- Dr. Chan noted that the difference in infection rates associated with home modalities may change when vaccination becomes more global. He also asked Dr. Weinhandl to speculate whether infections are being transmitted between patients or from staff. Dr. Weinhandl noted that the end of the analysis occurred during a period of decreasing infections in September 2020; evidence of attenuation is shown, and as the incidence decreases, the balance of risks and benefits decreases. A similar effect likely will occur with vaccination. Dr. Weinhandl commented that the COVID-19 infection rate in the dialysis population is about 90 percent correlated with state hospitalization, but identifying whether the dialysis facility has an effect or if community transmission is the primary method is difficult.
- Dr. Wilk asked whether differences in family circumstances, work opportunities, and other such factors were considered for home peritoneal dialysis patients and whether community transmission is a major confounder. Dr. Weinhandl suggested that an analysis with older data related to influenza could help confirm the results.
- Another participant commented on a study by her team that compared in-center and home dialysis, noting that COVID-19 rates were similar in the later part of 2020, which may suggest that infection control practices were implemented more widely over time. In any new pandemic, infection control practices may be implemented more slowly in centers. Dr. Weinhandl agreed that this theory seemed plausible and noted that the age associations evolved over time, showing that behavior changed over the course of the pandemic. The risk profile of patients dialyzing in

facilities changed rapidly and may reflect adaptations by nursing homes, but no changes in transportation. He suggested investigating how transportation acts as a risk factor.

- Dr. Schiller looked forward to the analysis of data from the fourth quarter of 2020 and the first quarter of 2021 and noted that Dr. Weinhandl’s data reflect what providers believe: that home dialysis was protective earlier in the pandemic, but protection in centers increased over time. She agreed that transmission usually occurred via the community, but steps taken in centers prevented outbreaks. Dr. Schiller also emphasized the importance of identifying successful prevention practices prior to the next infection season or next variant.

References

1. Weinhandl ED, Wetmore JB, Peng Y, et al. Initial effects of COVID-19 on patients with ESKD. *J Am Soc Nephrol.* 2021; 32 (6) 1444–1453.
2. Ziemia R, Campbell KN, Yang T, et al. excess death estimates in patients with end-stage renal disease—United States, February–August 2020. *MMWR Morb Mortal Wkly Rep.* 2021;70:825–829.

Recap and Charge

Kevin Abbott, M.D., M.P.H., NIDDK; Eric Wallace, M.D., UAB

Dr. Abbott commented on the very informed and passionate discussion during the first day, noting that he learned a lot from patients. Patients have concerns about safety and other issues, and providers need to find ways to communicate with patients and provide realistic reassurance. Mentors are highly regarded if they have experienced dialysis or therapy. Providers can be a significant barrier in the selection process. Although addressing training needs may be outside the realm of NIH research, patients and providers both must be persuaded and communicated with to define a better process and end product.

Dr. Wallace noted that although discussions so far have focused on existing problems, research on barriers must be coupled with research on interventions. Significant basic science research remains to be conducted, and members of the field need to determine how to encourage enthusiasm in younger generations for addressing the problems inherent in dialysis delivery regarding basic science, clinical research, and policy. He emphasized that all challenges are surmountable but require group collaboration to identify solutions.

Dr. Abbott pointed out that many discussions have focused on nursing homes and SNFs and emphasized that although these places can be reservoirs of certain infections, they are not the major focus of this conference outside of how they affect the home dialysis experience. He also noted that presenters had discussed the usefulness of telemedicine in providing more assistance at home, but had not discussed ways to mitigate the technology divide. He commented that this must be addressed if providers are relying on telehealth.

SESSION 6: Framework/Process Map

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK

Return to Framework of Discussion, Process Map (Maintenance, Avoid Failure)

Brigitte Schiller, M.D., Satellite Healthcare

Dr. Schiller framed her presentation on the theme of enabling patients to be successful with home therapies to live the best life possible. She pointed out that the providers’ task is to decrease or avoid the many complications to PD and home HD. Technique changes may occur for three reasons: (1) The patient receives a transplant or recovers function, which is the desired outcome; (2) the patient dies or

discontinues dialysis; (3) or the patient requires maintenance to avoid transfer to in-center HD. This maintenance could be required for either medical or nonmedical reasons. Medical issues may relate to dialysis, but nondialysis issues often relate to comorbid conditions. Nonmedical reasons include being overwhelmed or patient choice, which may be to go in-center even if providers do not know the reasons. The care partner also is an important component; for example, care partners may burn out.

Median time on therapy is about 2 years for both PD and HD. About 25 percent of patients, or less, have technique failure within the first year. In Canada, technique success for PD is about 83 percent in year 1, 71 percent in year 2, and 43 percent in year 3; for home HD, technique success is 82 percent in year 1, 76 percent in year 2, and 59 percent in year 3. American and Canadian patients show similar results over time.

Dr. Schiller emphasized that home dialysis is implemented to benefit patients; reasons for technique changes can include socioeconomic status, comorbidity, or center-specific factors, but not all of these can be changed. She reviewed the history of PD in Australia, noting that about half of the patients studied who stopped PD did so for infection-related reasons. Other reasons included inadequate dialysis, mechanical failure, and social-related reasons. Burnout may occur because of fear of adverse events, psychosocial issues, or caregiver burden. Dr. Schiller emphasized that providers must understand burnout to fix it and also must treat patients' and families' feelings seriously and accept them.

Dr. Schiller commented that the patient journey provides many opportunities to test hypotheses for optimization. As the ESRD community moves toward a "home-preferred" outlook, providers need to improve the system to ensure that people thrive. She emphasized that CKD requires training and support at every step along the journey.

References

1. Weinhandl ED, Gilbertson DT, Collins AJ. Mortality, hospitalization, and technique failure in daily home hemodialysis and matched peritoneal dialysis patients: a matched cohort study. *Am J Kidney Dis.* 2016;67(1):98-110.
2. Jacquet S and Trinh E. The potential burden of home dialysis on patients and caregivers: a narrative review. *Canadian Journal of Kidney Health and Disease.* 2019 (6); 1-7.

What Can We Learn from the Canadian Experience?

Christopher Chan, M.D., University of Toronto

Dr. Chan provided an overview of the Canadian system and potentially applicable nuances. He commented that the home system has developed well over the last decade in the United States. The rate among incident patients has grown, showing that progress has been made for home dialysis as a whole and especially for PD and preemptive transplant. However, the number of patients receiving in-center HD remains much higher. Dr. Chan emphasized the need to recognize that each system contains levers and modifiers, as well as recognizing the scale of use. He noted global differences in the practice of medicine and the preference of home dialysis. Australia, Canada, and New Zealand have higher prevalence of home dialysis; Dr. Chan commented that this is not always better, but it reflects differences in the system.

Dr. Chan pointed out that the single-payer dialysis system in Canada is relatively simple, serving 22,100 chronic dialysis patients in the country at an incidence rate of 202 patients per million population per year. Most dialysis units are hospital-based, and 25 percent of patients use home dialysis. Patients on HD are seen by nephrologists once a week, and the nephrologist reimbursement model is fee for service and modality independent. The bundles in the U.S. and Canadian systems do not include all elements the same way. Dr. Chan emphasized that the systems are designed to accomplish different goals, so the system might be the most important barrier.

Education also differs among countries. In Canada, New Zealand, and Australia, the minimum requirements for certification include exposure to home dialysis, which is not the case in the United States. Attitudes about home dialysis often are complicated; the culture in Canada is more inclusive. Dr. Chan emphasized that a workflow and culture of including home dialysis is key. Multicare CKD clinics, nurse navigators, and access navigators are standard in Canada, and regional training hubs are available.

Home dialysis barriers are not unique to the United States, but potential solutions are well published in the literature. Innovations must be implemented locally. Dr. Chan emphasized that now is the time for action and that thinking about solutions is more important than thinking about barriers. Efforts should be integrated into an ecosystem with industry partners and allied national societies. Dr. Chan suggested that the system should evolve toward a “home-preferred” strategy.

References

1. Blake PG. Global Dialysis Perspective: Canada. *Kidney360*. 2020;1 (2);115–118

What Can We Learn from the Pediatric Experience?

Joshua Zaritsky, M.D., St Chris Hospital for Children

Dr. Joshua Zaritsky outlined the pediatric experience with dialysis, noting the large gap between the number of home dialysis patients and prevalent PD patients. In pediatrics, the home dialysis and PD patient numbers are similar, but the system also is different. Dr. Zaritsky explained that severe geographic limitations have driven the home modality in pediatrics. Dialysis access is a factor given the difficulty of placing access in children, but caregiver availability is almost 100 percent. Home therapies also are easy to fit into an educational system. Adults can learn from the prevalence of patient and family education and the critical presence of provider education. Pediatric and adult systems are similar in socioeconomic issues, health literacy, and provider education levels.

Dr. Zaritsky noted that the only absolute contraindication to PD is the lack of a functional peritoneal cavity. The procedure is possible in small patients, patients with a vesicostomy or colostomy, patients with extensive history of abdominal surgery, patients with polycystic kidney disease, and patients with a ventriculoperitoneal shunt. Recently, the pediatric field has been collaborating more. The SCOPE dialysis collaborative has 50 participating centers, representing half of the PD centers. The collaborative is set up to implement three bundles, and peritonitis rates have decreased to the adult standard. Dr. Zaritsky emphasized that although the patient population has not changed, collaborative members have learned from one another.

Research gaps and opportunities include the possibility of promoting early use of peritoneal catheters. The collaborative shows that this is an untapped research area. The current bundle restricts the use of catheters to 3 weeks after placement, but the SCOPE collaborative could be used to design a multicenter study to look at an alternative early placement bundle. Medical literacy also must be addressed by identifying and eliminating gaps between populations to produce better outcomes.

The pediatric system could learn several things from the adult experience. Home HD pediatric literature is limited to single-center experiences, and utilization remains exceptionally low. No guidance has been published for patient selection in pediatrics; in adults, guidance on patient selection criteria for home HD is available from the National Institute for Health and Care Excellence and the MATCH-D.

References

1. National Institute for Health and Care Excellence. Guidance on home compared with hospital hemodialysis for patients with end-stage renal failure (TA48): <http://guidance.nice.org.uk/TA48>

Discussion

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- Dr. Ash asked if the risks of HD in children are a major limitation to expansion of home HD and whether the risks are as great as suggested. Dr. Zaritsky pointed out that although risks remain in small children, about half of the pediatric patients on HD are ages 15 to 21, so they are about the same size as adults and do not have many comorbidities. When asked if care partners feel limitations in caring for their own children, Dr. Zaritsky pointed out that most care partners serve as advocates for the children. He suggested that parents can be trained to conduct both PD and home HD and added that a month of training on-site could be added to fellowships.
- Dr. Onuigbo proposed adding a rule for home dialysis physician leadership. Dr. Chan commented that clinical champions always will be important parts of the home dialysis system—if someone is leading the way, the work culture will support home dialysis. He suggested that physician leadership at a task force level would increase visibility. Clinical leadership, visibility that leads to accountability at the national level, and a multifaceted ecosystem (including nursing leadership and the involvement of administrators) all are important to improve home dialysis uptake. Dr. Chan also noted the importance of valuing and celebrating progress made to date.
- In response to a question from Dr. Weiner, Dr. Zaritsky emphasized that the pediatric nephrology system requires change to increase recruitment. The workforce and its mentality are changing, and recruitment must be reinvigorated. He encouraged active research on how to improve recruitment.
- When asked to what extent other systems incorporate behavioral health and counseling to address burnout, Dr. Chan confirmed the importance of those issues and referred to the level of support in a system, which includes how much education is provided, what patients and care partners know about their expectations, and confirmation that patients are ready to go home when sent home. Dr. Schiller pointed out that her practice does not have an official program, but she learned from Canadians and Australians. She emphasized that the community must determine best practices to deliver home dialysis, including adaptations to how care should be delivered.

SESSION 7: Technologies

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK

How Can Novel Technologies Help Patients and Providers?

Stephen Ash, M.D., Indiana University

Dr. Ash discussed how novel technologies can help patients and providers. He emphasized that the goal should be to make dialysis therapy so simple and safe that most patients can perform it at home by themselves. Currently, the complexity of HD requires most patients to be treated in-center. Although removal of kidney failure toxins and fluid by dialysis is very effective, in-center dialysis is burdensome, requiring 3- to 4-hour sessions three times per week. The success of home HD is largely because of longer, slower, and more frequent treatments, resulting in less stress and damage to the heart and many other organs. Almost every part of HD needs improvement; Dr. Ash provided an overview of what is needed and potential solutions.

Blood access devices should be painless, secure, and long lasting, with minimal chance of infection, no blood leaks, and no vascular pathology. Attempts to reach this goal include the subcutaneous port and the Bentley button. Dr. Ash's team has proposed the placement of a silicone single lumen catheter into a

near-central vein. A single blood access point should connect to the patient's circulation with bidirectional blood flow. Several early HD machines used single lines or pumps; one benefit is that single access avoids the serious bleeds that can happen with isolated venous line disconnect.

Blood pumps should create constant line pressures automatically rather than constant flow rates. Dr. Ash showed examples of the development of this technology. He also emphasized that no air-fluid interface (i.e., drip chambers) should be present in the system and showed several examples of technology development in this area. Regarding anticoagulation, no dialyzer clotting should occur for the length of use, and systemic heparin should not be required to achieve this. Heparin-grafted membranes decrease, but do not eliminate, clotting, and regional citrate anticoagulation works well in the hospital but is too complicated for standard HD. A novel approach reverses the use of hollow fibers by putting blood outside and dialysate inside, which diminishes clotting. This approach will require new membranes with a smooth surface on the outside.

Dialysate water volume should consist of a few liters of water and a sorbent column removing uremic toxins. Several technologies have provided sorbent dialysis in the past, and four current companies are creating new home dialysis machines using similar components. The sorbent columns are effective, but controlling blood electrolytes is complicated. Excess fluid in the patient should be measured automatically and an ultrafiltration rate set to remove dry weight. Dialysis machines accurately control the rate of fluid removal from a patient, but the exact fluid excess each patient has is difficult to determine. Dry weight usually is found by trial and error, and such measures as a physical exam, blood pressure, and recent weight gain are inexact measures of extra fluid. Artificial intelligence has the potential to find dry weight better than nephrologists.

In terms of physiologic monitoring, machine-monitored blood pressure, cardiac and lung function, blood purity, and organ perfusion can allow the machine to provide optimal and safe therapy. These technologies now have evolved into wearable and miniature sensors. Chemical monitoring can assess uremic toxins continually and adjust chemical function of dialysis. Because dialysate concentrations control body chemistries and dialysate is chosen based on pre-dialysis blood tests conducted monthly, blood chemistries too high before dialysis often are too low afterward and can change if the diet changes. Ideally, a dialysis machine that can conduct chemical tests could compensate for this issue. Dr. Ash presented several promising technologies in this area.

The last area to consider is the physical steps of dialysis. A machine that can be operated in a completely hands-off manner—including bolus fluid administrations, priming, and rinsing—would be ideal. Many of these steps could be automated, and home dialysis machines now are being developed and marketed that have automated some of these steps, but often these are produced by start-up single-product companies rather than large dialysis companies.

The PD gaps include the need for improved access, measurement of intraperitoneal volume, antibacterial catheters and solutions, efficiency to allow overnight treatments, and regeneration to remove toxins from outflow PD dialysis fluid.

Dr. Ash summarized that other life-supporting therapies are used widely at home. With current technologies, hemodialysis is complex, sometimes risky, and often painful. The effects are unseen and poorly monitored. Important endpoints, such as dry weight, are nebulous, and current equipment uses large amounts of space, power, and water. Many new technologies and ideas are available to improve each component of hemodialysis, but are hindered by the difficulty of moving these ideas and technologies into production and marketing. Dr. Ash commented that patients, technicians, nurses, and physicians have become complacent with in-center dialysis using outdated technology. Many

stakeholders can help promote home dialysis, including patients, nurses and technicians, physicians, entrepreneurs, major companies, researchers, the NIH, the CMS, and professional and patient societies.

References

1. Sharma MK, Wieringa FP, Frijns AJ, Kooman JP. On-line monitoring of electrolytes in hemodialysis: on the road towards individualizing treatment. *Expert Rev Med Devices*. 2016;13(10):933-943.
2. Stephen Ash, Oral sorbent for removing toxins of kidney failure combining anion and cation exchangers (2020). US Patent 10668098

Discussion

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- A participant asked whether a hybrid dialysis machine, that could perform both hemodialysis and peritoneal dialysis can help with retaining patients on home therapies. Dr. Ash agreed such a machine would be a good idea and commented on improvements in making PD fluid. He noted that because satisfactory fluid for intravenous infusion on site (in hemodiafiltration) sterile fluid also can also be made for PD, using sorbent and filtration technology. He emphasized the importance of also simplifying both HD and PD; the latter remains considerably easier for most patients. Dr. Ash added that a proportioning system for PD alone will be very helpful in home dialysis. He also noted that dialysate regenerating columns previously were used in the Redy® system and are again being developed, a gap remains today between devices that are wearable or highly portable and those that are the size of current transportable home HD machines.
- A participant also asked about advances in nocturnal home HD therapy, such as remote monitoring. Dr. Ash clarified that one benefit of home HD is the ability to use sleep hours as the standard therapy time. Nocturnal dialysis requires a flow rate that works with a single needle; a slow dialysate flow provides an increased length of operation to saturation of the column. Nocturnal home HD also could be performed every other day for 8 hours.
- Dr. Ash suggested that achieving all the above goals would make starting HD much easier whether in centers or at home. Dr. Ash agreed and commented that some patients are hesitant after seeing nurses struggle to implement the current technology in-center.
- Dr. Wallace pointed out that remote patient monitoring has been used for a long time, but researchers have not studied how to use the data in a meaningful way. Dr. Ash suggested that ideally, a machine should be able to assess a situation and respond directly or instruct the patient. He agreed that most home monitoring has been unsuccessful and pointed out that one of the most common causes of false alarms is Wi-Fi failure.
- Another participant commented on a self-closing needle in development (Hemotek Medical) that would automatically close if it becomes dislodged, which would be useful for nocturnal home HD.

SESSION 8: RESEARCH STUDIES

Moderator: Kevin Abbott, M.D., M.P.H., NIDDK

Challenges in Research in Home Dialysis

Eric Wallace, M.D., UAB

Dr. Wallace explained that funding for kidney-related research in general is low. Over the past 2 years, 46 papers related to clinical trials for PD were published, and only three of these occurred within the United States. Challenges for basic science and translational research include the difficulty of finding a mentor given the limited options for mentors knowledgeable in PD-related science with a reputation in the NIH. Research techniques can be a challenge to learn—placement of PD catheters in mice is difficult, dialysate is difficult to make or access, and learning techniques may require travel. Dr. Wallace suggested that an O’Brien Center for Home Dialysis might be an option.

Challenges to clinical trials also persist. Some challenges are regulatory; home dialysis in the United States can be owned by the university, but it may be a separate entity owned by a LDO. When multiple research organizations are involved, paperwork increases and speed decreases. Most studies in home dialysis must be multicenter to have a chance at statistical significance, which poses a problem with the pressure to publish when numbers of prevalent and incident patients are low.

One major issue in the field is the lack of a standardized lexicon. Studies are difficult to compare because researchers may have different definitions for such concepts as “urgent start,” “peritoneal membrane failure,” and “technique failure.” Another challenge for large retrospective studies is that the USRDS does not gather some important data, such as peritonitis rates, access-related issues, and analysis of technique failure and its causes in home dialysis. U.S.-based and international research consortiums and partner networks—such as Peritoneal Dialysis Outcomes and Practice Patterns Study, Standardized Outcomes in Nephrology-PD, and North American Research Consortium-PD—offer a way to reduce logistical barriers.

References

1. Wallace EL, Fissell RB, Golper TA, et al. Catheter insertion and perioperative practices within the ISPD North American research consortium. *Perit Dial Int*. 2016;36(4):382-386.

Discussion

Moderator: Shannon Givens-Bradley, M.P.H., NIDDK

- Dr. Ash commented that many nephrologists choose bench-top physiology and cellular biochemistry as their research focus because these areas are more likely to be funded given the preference for biological sciences. He recommended development of a Small Business Innovation Research (SBIR) study review panel (SRP) that focuses on improving therapies for ESRD.

BREAKOUT DISCUSSIONS: PATIENT SAFETY, RESEARCH, AND TECHNOLOGIES

Focusing on Patient Safety in Home Dialysis—Policy Implications, Inpatient Readiness, Outpatient Availability

Group Leaders: Janice Lea, M.D., Emory University; Darryl Taylor, Patient; Vanessa Evans, M.A., Fresenius Medical Care

Designing Home Dialysis Research Studies

Group Leader: Jenny Shen, M.D., The Lundquist Institute, University of California, Los Angeles

Advancing Technologies to Meet Patient and Provider Needs

Group Leaders: Susie Lew, M.D., The George Washington University; Stephen Ash, M.D., Indiana University

Reports from Breakout Sessions

Moderators: Shannon Givens-Bradley, M.P.H., NIDDK; Kevin Abbott, M.D., M.P.H., NIDDK

Dr. Abbott invited the breakout group leaders to present their reports.

Patient Safety

Dr. Lea presented the group's main points of discussion. Better educational tools and support for troubleshooting are needed to ensure that patients feel safe and comfortable at home. Patients need to know how to respond to both medical emergencies and local emergencies, such as loss of power. Patients also need to be well educated on procedures, and adequate resources must be available within the community. Reimbursement for staff assistance with home dialysis, especially early in the process, is a policy issue. Patients who receive appropriate treatment rarely need significant staff assistance, but it should be available. Nursing staff shortages must be recognized as a limitation.

Ideas are needed for how to develop and support telehealth, which is immensely helpful for patient safety. Remote monitoring is not being used effectively, but telehealth could retrain patients who have issues with their treatment; examining the home environment and technique would be helpful. A recent CMS ruling limits reimbursement for telehealth but approves telephonic communication, so Dr. Lea expressed the hope that some ability to use telehealth would continue. Robust studies would support future positive legislation for telehealth. Dr. Lea emphasized that although technologies that would make home dialysis easier for patients have been discussed, technology must be combined with other elements, especially education.

The group also discussed the concerns of patients who feel pushed to engage in home dialysis when they may not have appropriate resources or be good candidates. The group emphasized the importance of ensuring proper patient selection and ensuring that patients are offered appropriate technology and access to providers who promote home dialysis. The benefits of remote monitoring also must be explored, such as whether it is safer, whether outcomes are better than the standard of care, what elements should be monitored, and how safety should be defined.

Research Studies

Dr. Jenny Shen summarized the group's main discussion points. One key issue is whether to prioritize the initiation of dialysis or its maintenance. Focusing on increasing enthusiasm for home dialysis may provide momentum for more patients to start home dialysis. Home dialysis requires pragmatic implementation and community-based research. Local solutions must be balanced with large studies that will be funded and published. The group also discussed whether a role exists for funding to establish best practices. More collaboration is needed among researchers, patients, care partners, dialysis organizations, and funders. The group agreed that the lack of standard definitions is a barrier; these could be developed in tandem with other research. The group also discussed how to generate excitement for home dialysis beyond the nephrology community, how to publicize that it exists, and how to build momentum that will increase support for research.

Technologies

Dr. Susie Lew explained that her group based their discussion on Dr. Ash's presentation and addressed both HD and PD. Patients on home HD prefer remaining at home, and techniques that keep them at home should be prioritized, such as having a catheter or technologies that make performing dialysis easier. Individualized treatment is needed—patients in the group felt that laboratory results are measured only before dialysis and that no point-of-care treatment was provided. The group recommended the development of technology to measure and confirm target weights and ways to measure laboratory results using point-of-care tests so therapy can be tailored to the most accurate results. The main concern for patients on PD was the number of boxes delivered to their home every month. Patients want to see

innovation in detection of peritonitis at an earlier stage, ways to reduce or reclaim protein in dialysis fluid, and ways to change the fluid for ultrafiltration. Dr. Lew emphasized that providers need to focus more on how patients feel than on laboratory results. Group members were very enthusiastic about implantable kidneys and using telehealth and remote monitoring to improve quality of life.

Discussion

- Dr. Ash commented on the importance of staff assistance, suggesting that a previous program supporting staff-assisted home HD should be reinstated. Dr. Lea commented that some clinics provide staff assistance, but only to patients with private insurance; she agreed that it should be made more widely available. Dr. Chan confirmed that funding formulas are available for staff-assisted home dialysis in Canada. He added that nephrologists are reimbursed independent of modality. Dr. Weinhandl suggested that the transition to Medicare Advantage might improve coverage for staff assistance.
- Ms. Evans commented on the need for more research on innovative ways to reach patients' blood that are safer and less traumatic. Peritoneal dialysis does not last indefinitely, so patients who do not receive a transplant will need to do HD eventually. Dr. Shen commented that patient comfort is an important consideration in both starting and maintaining dialysis.
- Dr. Ash commented on innovative ways of conducting chemical assays, noting that many point-of-care instruments could be used in the home but require testing blood. He suggested that the ideal solution would be a machine that can infer blood chemistry from dialysate concentrations. Dr. Abbott noted that the iStat machine can identify electrolytes in a finger stick or small amount of blood; Dr. Evans commented that providers must inform patients of such machines and make them accessible.
- Dr. Kimmel asked Dr. Shen whether her group identified the most important research question to address. Dr. Shen explained that her group's main discussion was whether to focus on increasing the number of patients who start home dialysis or maintaining patients already on home dialysis. She noted that initiation includes modality and PD candidate evaluations.
- Dr. Schiller emphasized that this workshop exists because providers and researchers recognize the potential to increase use of home dialysis at this time. Regarding the most important question to address, she noted that patients often are very afraid of going on dialysis, and providers can look for ways to improve the system, such as adding a human touch or adjusting the care delivery model. Dr. Ash added that providers should push in every direction to simplify the technology and make it safer and more responsive to individual patient needs. He reiterated that an SBIR SRP focused only on dialysis applications or a prize competition could spur technology improvements. Dr. Schiller pointed out that the number of nephrologists committed to home dialysis also must be increased and implementation issues must be addressed.
- Dr. Shen suggested that a checklist for PD candidacy could improve initiation rates, pointing out that many patients are not offered a choice and providers need more education on how to engage and evaluate patients. Dr. Wallace agreed that many patients do not receive information sufficient to encourage them to choose home dialysis. He pointed out that the system makes starting patients on home dialysis difficult and suggested developing a team that could create a better system at specific locations to improve uptake.
- A participant suggested that maintenance issues limit growth; patients need to meet certain goals to maintain CMS coverage, but the goals may not be scientifically appropriate for every patient.

- Another participant (ESRD Network 12) pointed out that her group contracts with the CMS and includes quality improvement activities for increasing home modalities. She encouraged participants to contact the ESRD Network for help with education, webinars, or community coalitions.
- Dr. Abbott asked patients to comment. Ms. Evans explained that she chose home dialysis to spend more time with her family, who now assist with her dialysis. She emphasized that care partners are involved in the process of care. She also added that patients should learn as much as they can to have ownership over their treatment. Ms. Gedney commented that home dialysis was offered to her only after many years of CKD, and it has improved her health, life, and independence.
- Dr. Lew pointed out that the “big picture” regarding technology is that many options exist, but implementing them in the home health arena is a challenge. She commented that the highest priority problem in PD is reducing the number of supplies patients need to keep at home, such as by making their own fluid. Ms. Evans agreed that streamlining and simplifying procedures would be very helpful. She added that researchers need to consider the entire scope of any changes—for example, homemade fluid may require an increase in time required to sterilize equipment.
- Another participant noted that his company is developing point-of-care solutions and PD devices, but the existing dialysate solution providers will not sell solutions to smaller companies, which is a challenge for new companies to enter the field. He suggested putting more pressure on existing players that make dialysate.

Conclusion—Closing And Future Directions

Robert Star, M.D., NIDDK

Dr. Star summarized the workshop conclusions and noted future directions.

Main Considerations

Dr. Star emphasized the importance of shifting to a precision or personalized dialysis mindset, which would offer the right therapy for every person at the right time. Increased patient choice and meeting patients where they are is critical, and these concepts must include all personal, medical, and social determinants of health issues. Considerations include the evidence needed to promote a shift to home dialysis and any knowledge that remains unknown or has been hidden. Evidence that home dialysis is better than in-center dialysis is lacking. Evidence is needed to show that patients thrive on dialysis with improved quality of life and that home dialysis helps patients feel better, reduce fatigue, hold a job, and maintain flexibility and independence. Information on home dialysis is hard to find, and both patients and providers need information on how to overcome their fears. Proper education and training is needed at all levels. Culture and system change is needed, and a peer-to-peer network could help with these improvements. Patients also need to be able to “own” their treatment and accept that dialysis is part of their life. Researchers must identify barriers—including social determinants of health and equity—and use a structured system and personalized approach to address these barriers. Equity is critical to address because some barriers, biases, and discrimination disproportionately exclude marginalized people.

Dr. Star emphasized that improving home dialysis is a marathon, not a sprint.

Steps Needed for Personalized Dialysis

In pre-kidney failure care, awareness and patient choice must be improved, and patients must be provided with gradual education, decision tools, and the pros and cons of each method. Patients must have the chance to discuss their fears, and a peer-to-peer network of mentors or ambassadors could help improve

their comfort. Providers can help identify and overcome barriers in this area. When initiating kidney failure treatment, improved home dialysis methods and an optimized environment are needed. Training of clinicians, fellows, and patients must be improved, including virtual or personal training. A mentor network could help as well, but care partners and assisted care are critical parts of the care team. For maintenance of home dialysis, safety must be monitored, and trouble-shooting solutions must be offered. Therapy should be prescribed based on QoL targets, and methods to keep people on home dialysis and help them avoid burnout are needed. The national environment should be optimized, and mentors are needed for clinician care teams. To maintain quality of life, methods to standardize and measure bloodstream infections, peritonitis, and PD membrane health must be developed. Outcome data are needed on quality of life, survival, emergency visits and hospitalizations, retention, and switches.

Technology Development Opportunities

Opportunities include improving ease of use through better or simpler options and designing new technologies that are smarter or more portable. Technology also can help address patients' pain or fears, and machines can be developed that monitor and mitigate safety issues and individualize treatment to metabolic demands. Technology must address the space, power, and water requirements of homes. Telehealth and remote monitoring must be considered. Peer mentoring could be another area for technology development. Maintaining peritoneal membrane health and residual renal function also could be assisted by technology.

Levers for Personalized Dialysis and Final Thoughts

Dr. Star highlighted the need for evidence previously discussed, training, and telehealth and addressing the technology gap and policy and payment needs. Barriers must be identified at the basic science, provider, patient, systems, policy, and payment levels, and cultural factors embedded in the system should be considered. Dr. Star encouraged participants to contact the KUH with comments and emphasized that patients are the best source of information and critical to progress.

Adjournment

Drs. Abbott and Star thanked the participants for attending the workshop and for their insights. The meeting was adjourned at 2:57 p.m. EDT.