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Proceedings of a Workshop to Promote Community Health Worker Interventions in Nephrology

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ABSTRACT

Latinx populations face a higher burden of kidney failure and associated negative outcomes compared with non-Latinx White populations, despite sharing a similar prevalence of CKD. Community health worker (CHW) interventions have been shown to improve outcomes for Latinx individuals, but they are largely underutilized in kidney disease. We convened a workshop of four ongoing kidney disease CHW programs to identify successes, challenges, potential solutions, and needed research to promote CHW programs for Latinx individuals with kidney disease. Key points from the workshop and recommendations for intervention and research are highlighted. Facilitators of program success included prioritizing trust-building with participants, enabling participants to determine what aspects of the intervention were needed, providing participants with tools to help themselves and others after the intervention, and taking a trauma-informed approach to relationships. Challenges included persistent systemic barriers despite successful care navigation and low recruitment and retention. Research is needed to capture the effect of CHW interventions on outcomes and to determine how to implement CHW interventions for people with kidney disease nationwide.

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BACKGROUND

Latinx (gender-inclusive term, includes Hispanics, Latino/a) populations in the United States face a higher burden of kidney failure and associated negative outcomes compared with non-Latinx White populations, despite sharing a similar prevalence of CKD.[1–3] This discrepancy is a reflection of lower predialysis access to care, unique barriers to health care navigation, and health-related social needs among Latinx individuals.[3–7] Care deficiencies are profound for the 11 million undocumented immigrants of which 78% are Latinx.[5,8] Interventions that improve access to care, optimize care navigation, facilitate disease self-management, and address health-related social needs for Latinx individuals are needed and have the potential to eliminate kidney disease disparities.

Programs that train community members who have lived experience to provide disease education and advocacy, facilitate behavioral change, and assist with health care and community resource navigation have been shown to improve outcomes for Latinx individuals, but they are largely underutilized in kidney disease.[9–17] There are a number of terms for this role, including community

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Table 1. Kidney Disease Community Health Worker Programs Represented at the Workshop and Key Lessons Learned

Intervention	Goal	Description	Lessons Learned
CHW-led care navigation for Latinx individuals with early CKD[18]	Facilitate care connection for Latinx immigrants who attended community screening events and were found to have risk factors for kidney disease (BP ≥130/80 mm Hg, body mass index >24 kg/m^2) and/or albuminuria >30 mg/g	• CHW provided individualized support in obtaining health insurance and primary/nephrology care, disease education, and assistance navigating health care and community resources to address health-related social needs	Successful elements: • Prioritize trust and rapport • Prioritize health-related social needs and safety concerns • Optimize sense of control and transition to independence • Individualize interventions; meeting schedule and goals determined by participants • Important CHW characteristics: ○ Shared experience with kidney disease or knowledge ○ Shared language/culture ○ Heightened awareness of trauma Challenges: • Barriers persist despite successful care navigation (*i.e.*, ineligible for community resources due to documentation status) • Culturally sensitive health care not always available • Challenges with recruitment and retention: ○ Lack of readiness ○ Competing priorities ○ Mistrust of health care
CHW-led dialysis navigation for Latinx individuals with kidney Failure[12]	Facilitate care coordination and transplantation for Latinx individuals with kidney failure receiving dialysis	• CHW provided individualized support with advanced care planning, care coordination, and counseling on the importance of diet and mental health	
Peer-mentorship to improve outcomes in patients receiving maintenance hemodialysis[20]	Reduce acute care utilization among people (Latinx and non-Latinx) with kidney failure receiving dialysis	• Patients chosen by dialysis facility staff to mentor other patients (up to three at a time) and were financially compensated • Mentors contacted mentees weekly for 3 mo and provided support and education	
Patient-led navigation for people receiving emergency-only dialysis	Facilitate care coordination and transplantation for Latinx immigrants with kidney failure receiving emergency-only dialysis	• CHW was a Latinx individual with kidney failure who transitioned from emergency-only hemodialysis to kidney transplant • CHW helped others obtain health insurance and provided support, education about treatment options, and assistance with health care navigation	

CHW, community health worker.

health worker (CHW), navigator, peer navigator, peer support specialist, peer mentor, popular opinion leader, and promotora. In this article, we use the term CHW and refer to the individual receiving the intervention as a mentee. A greater understanding is needed of how CHWs could optimize care for people with kidney disease, given the complexity of kidney disease management (*i.e.*, transitioning to dialysis and navigating evaluation for transplant). We aimed to learn from four ongoing kidney disease CHW programs to identify implementation successes, challenges, potential solutions, and needed research to promote CHW programs for Latinx populations with kidney disease.

The University of California Los Angeles Clinical and Translational Science Institute awards catalyst grants to support team-building activities that advance translational science and promote collaboration across disciplines. We convened a daylong workshop in October 2022 in Los Angeles that was funded by the catalyst grant with additional funding from the National Kidney Foundation. The workshop included a diverse group of people with kidney disease, dialysis social workers, kidney disease CHWs, community organizers, and kidney disease providers who were identified by the organizers on the basis of their known involvement with kidney disease CHW programs for Latinx individuals. Workshop discussions were guided by the experience of the participants who provide these interventions. Program elements were considered successful if they facilitated program goals and objectives. Key points from the workshop and recommendations for intervention and research are highlighted.

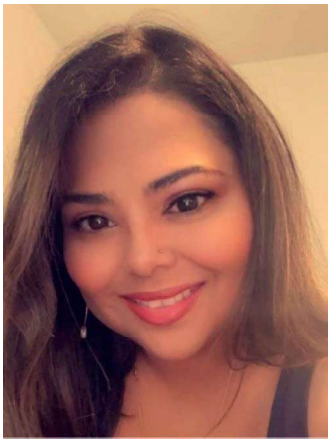
INTERVENTIONS REPRESENTED AT THE WORKSHOP

The program organizers (JS and LC) selected CHW programs using snowball sampling, and the number of programs invited was determined by funding availability. Four kidney disease CHW programs were represented at the workshop, three that were led by CHWs (Table 1, Box 1), and one that consisted of numerous peer-mentors. The interventions each targeted Latinx individuals at different points along the spectrum of kidney disease. All of them assisted with care navigation and promoted activation mentees.

CHW-led Care Navigation for Latinx Individuals with Early CKD

An intervention in Austin, Texas, connected people with albuminuria or kidney disease risk factors at community screening events to medical care. This program partnered a CHW who works for a local health entity with National Kidney Foundation community screening events. Individuals who attended the screening events underwent the measurement of BP, body mass index, and albuminuria, and if eligible, they were invited to work with a CHW. Eligibility criteria included Spanish-speaking Latinx adult found to have at least one of the following: (*1*) measured BP ≥130/80 mm Hg, (*2*) body

Box 1. Kidney disease CHWs at the workshop and why they feel this work is important.

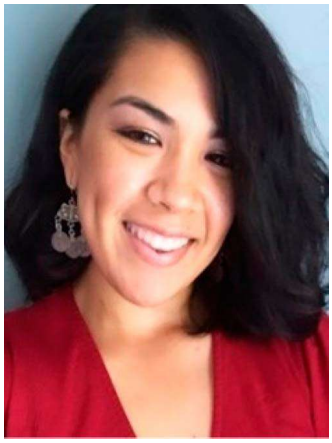


I believe that the work done by CHWs is very important. We are part of a team that serves as liaisons: Working to create bridges between health care system and the most underserved community members. We do this by providing outreach, valuable education, social support, and advocacy for patients with chronic diseases. This work in turn helps nurses and doctors as it brings a better understanding of the patient's needs and the challenges they face while trying to navigate the health care system, ultimately allowing a better quality of life to those we serve

-Evelyn Cruz, community health worker in Texas

When I began working with Dr. Lilia Cervantes, I found an opportunity to help others. I was drawn to her work of addressing end-stage kidney disease with the Latinx community since my family has a history of kidney disease. I lost my father because of it, and I knew how challenging treatment was for undocumented patients. Dr. Cervantes' work taught me that there were ways to demonstrate the dire need through research and how that could incite health care policy changes. I used what I learned and what I knew as a Latina myself to build rapport with patients through individual visits and case management. I learned that my father's outcome could have been a different one if only I had known what I know now. I realized that what the community needs is more individuals with the tools to advocate for them; therefore, becoming a community health worker became not only a job but my mission in life

-Claudia Camacho, community health worker in Colorado



I am a transplant recipient who spent nearly a year receiving emergency-only hemodialysis due to my immigration status in Georgia. During that time, I met many who also suffered from kidney disease and did not have proper treatment. I was inspired and determined to do everything in my power to push for change in any capacity. This work is very close to my heart, as I saw and lived first-hand the result of health inequities for the Latinx community. It is important to continue to learn, talk, and push for policy change in states like Georgia, where there are very few resources for immigrant communities with chronic conditions

-Luz Baqueiro, peer mentor in Georgia

mass index >24 kg/m^2, or (3) >30 mg/g albuminuria on point-of-care testing. Over the subsequent 6 months, the CHW provided disease education, facilitated connection to community resources to address health-related social needs and barriers to care, and helped mentees obtain insurance and primary care. Preliminary findings indicated acceptability of the intervention as a way to improve access to care for Latinx individuals.[18]

CHW-led Dialysis Navigation for Latinx Individuals with Kidney Failure

A community research steering committee in Denver, Colorado, comprised individuals with lived experience, caregivers, and clinicians led qualitative research that informed the development of a peer CHW intervention for Latinx with kidney failure receiving outpatient hemodialysis. A one-arm prospective study of the CHW intervention that provided individualized support with advanced care planning, care coordination, and counseling on the importance of diet and mental health was designed. A pilot test among 40 Latinx individuals with kidney failure receiving in-center hemodialysis to assess feasibility, acceptability, and intervention dose was conducted in 2017. Findings from this study demonstrated that this intervention was feasible and acceptable.[12] A randomized controlled trial assessing the effectiveness of this intervention on patient-centered and clinical outcomes was completed in 2022, and preliminary findings indicate that CHW interventions improve patient-centered outcomes.[19]

Peer-Mentorship to Improve Outcomes in Patients Receiving Maintenance Hemodialysis

A multicenter randomized controlled trial was conducted in Bronx, New York, and Nashville, Tennessee, to test the effectiveness of peer-mentorship to reduce hospitalizations and emergency department visits among 140 patients receiving

hemodialysis.[20] Mentors (n=16) were patients receiving dialysis who were recommended by providers or dialysis facility staff. The term mentor is used because these individuals did not receive official CHW certification. They were trained over a period of 4 weeks on dialysis-related metrics and mentoring skills. The mentors were then assigned up to three mentees at a time that were patients who were on maintenance hemodialysis and at high risk for hospitalization. The intervention comprised telephone contact between mentors and mentees on a weekly basis over a 3-month period. The mentees were followed for 12 months for hospitalization and emergency department visits. Both mentors and mentees were financially compensated for their participation. Because of the high prevalence of Latinx individuals in New York City, the study team purposively recruited bilingual mentors (Spanish and English) in the Bronx, totaling 5/16 of mentors recruited, and matched them to Spanish-speaking mentees. The primary analysis testing effectiveness is yet to be completed, but feasibility and acceptability of the training program and intervention were demonstrated.

Patient-led Navigation for People Receiving Emergency-only Dialysis

A Latinx individual with kidney failure in Georgia transitioned from relying on emergency-only hemodialysis to successfully receiving a kidney transplant. She did this by learning and navigating the medical system and purchasing private health insurance. She now volunteers her time supporting others who rely on emergency-only hemodialysis; she provides emotional support, advocacy, and informal education on how health insurance works, how to navigate the health care system, and treatment options for immigrants with kidney failure.

FACILITATORS AND CHALLENGES FOR CHW INTERVENTIONS

Workshop participants shared their personal experiences and insight into important intervention components that worked well, the challenges they faced, and potential solutions.

Successful Elements

Workshop participants identified program elements that promoted intervention success. For example, participants agreed the first encounters with mentees had to be about trust and rapport. Relating with mentees mentally and emotionally, and promptly addressing any health-related social needs was critical before providing education or other parts of the intervention. It was particularly important to understand what was distressing for mentees and ensure they felt stable before disease self-management was possible. In-person encounters were felt to optimize relationships, but workshop participants noted the need for flexible virtual options for people with immobility, time limitations, or during waves of the coronavirus disease 2019 pandemic.

Allowing the interventions to be mentee-driven facilitated engagement. Giving mentees the power to determine what goals they wanted to address and when, where, and how often they wanted to meet with CHWs dissipated power differentials and promoted mentees' sense of control.

Teaching mentees how to navigate medical systems was an essential component of all the interventions discussed, and having mentees transition from learner to doer enabled lasting change. Empowering mentees to do things themselves also allowed them to become teachers and disseminate information to other members in their community.

Workshop participants recommended for CHW interventions to take a trauma-informed approach because people with kidney disease experience substantial illness-related trauma that could be compounded in some by trauma from the immigrant experience. Trauma-informed care consists of screening for and recognition of past traumatic experiences, understanding the effects of trauma, emphasis on emotional safety and avoiding triggers, and knowledge of helpful treatments for trauma, and should be considered when working with all individuals with kidney disease.[21–25] Heightened awareness of the potential for retraumatization of CHWs is important, given their shared experiences with mentees. Training CHWs in motivational interviewing was felt to promote lasting behavioral changes among mentees.

Workshop participants identified the need for a clear feedback system between CHWs and their parent institutions for troubleshooting barriers. This enabled necessary adaptation and cultural tailoring and prevented CHW burn-out. Having a team of CHWs that provided cross-coverage prevented burnout while increasing availability.

Workshop participants identified essential CHW characteristics. Sharing a lived experience or defining characteristic with mentees was critical. Whether that shared experience was kidney disease or the same language or culture, mentees wanted to work with someone who understood what they were going through. Sometimes mentees felt more comfortable working with a CHW who identified as the same gender. Workshop participants perceived that being accountable and responding to mentees' needs in a timely manner made mentees feel supported, as long as there was transparency about CHW availability. If CHWs did not have experience with kidney disease, they needed to have comprehensive training on the associated physical and psychosocial effect and the illness-related trauma it can carry.

Challenges and Potential Solutions

Workshop participants noted persistent systemic barriers despite successful care navigation. For example, citizenship or legal immigration status is required to qualify for Supplemental Nutrition Assistance Program benefits, and resources to address food insecurity for undocumented immigrants were not always available. Sometimes this prevented CHWs from helping mentees with food insecurity, a known driver of poor health outcomes.[26–28] Despite connection with health care services, quality language interpretation and language concordant education materials were

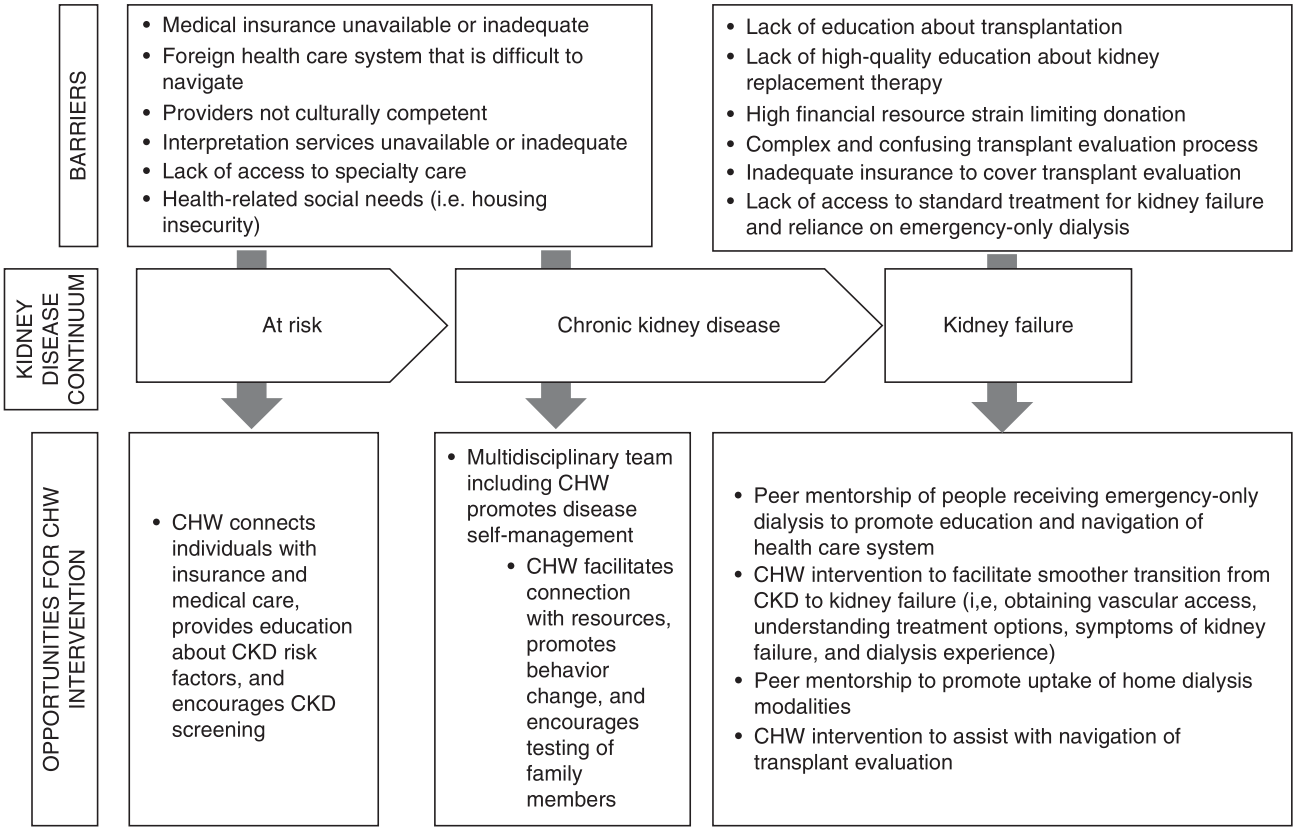


Figure 1. Opportunities for CHW intervention along the continuum of kidney disease. CHW, community health worker.

not always available, perpetuating communication barriers and making it difficult for mentees to manage care after the intervention.

Workshop participants noted challenges with recruitment. Reasons included mentee lack of readiness, competing priorities, and mistrust of the medical system. Suggested solutions included hiring a bicultural intervention staff, offering a financial incentive, allowing for program flexibility, and engaging with mentees in trusted community locations. For example, going to community locations to screen for kidney disease and then providing education and enrolling mentees at those locations was felt to increase enrollment in the Austin program. If the CHWs were associated with locations where mentees felt safe, they were more likely to engage.

Participants noted challenges when studying CHW interventions. CHW interventions were felt to work best when they were mentee-driven and individualized, making them difficult to standardize or determine the adequate intervention dose. Traditional clinical outcomes, such as change in kidney function, might not capture the breadth of a CHW's effect, and careful consideration and intention when choosing a study outcome is needed. Varying resources in different communities could limit implementation in certain locations. When conducting CHW research, participants felt it was essential to hire a full-time CHW that was dedicated to the study. This minimized competing responsibilities for the CHW and facilitated optimal data collection and management.

OPPORTUNITIES FOR INTERVENTION AND NEEDED RESEARCH

We identified situations in which CHWs might be used along the spectrum of kidney disease (Figure 1). To the best of our knowledge, many of these interventions have not been attempted or tested.

Workshop participants identified the areas of needed research. Before implementing any CHW intervention, it is necessary to determine the prevalence of kidney disease or risk factors in a given community as well as using qualitative research to better understand the most trusted locations from which to recruit. Qualitative research with CHWs is needed to understand what drives them, essential training, how they leverage their assets or resources, and what communication styles they use. Participants stressed the importance of anchoring CHW research to the community served, such as forming community advisory boards, to design interventions and conduct research that had broad effect and advanced social change. There is very limited evidence on the effect of CHW interventions on risk factor control, kidney failure prevention, use of various kidney replacement therapy

modalities, kidney transplantation, and other outcomes, and large-scale randomized trials in this space are greatly needed.

CHWs are community members who share a lived experience with the people they serve. CHW interventions hold tremendous potential to address kidney health inequities and improve care for Latinx and other historically minoritized racial and ethnic populations. At this workshop, four ongoing CHW programs were represented and discussed, and successful traits and challenges were identified. Research is needed to capture their effect on outcomes and determine how to implement CHW interventions for people with kidney disease nationwide.

DISCLOSURES

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Writing – review & editing: Luz Baqueiro, Lilia Cervantes, Ladan Golestaneh, Tessa K. Novick, Michelle Osuna, Sylvia E. Rosas, Jenny Shen.

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