

Structural and Psychosocial Challenges Among Underserved Patients Receiving Hemodialysis During and Beyond the COVID-19 Pandemic: A Qualitative Study



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Rationale & Objective: Racial and ethnic minority groups in the United States are disproportionately affected by chronic kidney disease and progressive kidney failure and face significantly more socio-economic and psychosocial challenges. However, how such patients' social environment and stigmatization shape their illness experiences and abilities to cope before and during the coronavirus disease 2019 (COVID-19) pandemic has not been well documented, even as social scientific research predicts these groups' exponential vulnerability.

Study Design: Qualitative study using semi-structured interviews to elicit individual patient narratives about their personal illness experiences before and during the COVID-19 pandemic, any challenges they faced, and their sources of support.

Setting & Participants: Using purposive sampling, we recruited 20 adult patients receiving maintenance hemodialysis from centers affiliated with a safety-net hospital in Boston, Massachusetts.

Analytical Approach: Interviews were audiotaped, transcribed, and analyzed using thematic content analysis to identify patients' challenges and supports before and during the pandemic.

Results: Of the 20 patients in the study, 9 were women, and 18 self-identified as Black or African American. Three main themes emerged, whereby most patients described: (1) stigma and stigmatization as a central element of their life experience; (2) the pandemic as a difficult experience but not a complete rupture from their prepandemic life; and (3) social networks, particularly family, friends, and religious communities, as sources of support crucial to coping with their debilitating illness.

Limitations: Whether the findings apply to other settings is unknown, as participants were recruited from centers in a single safety-net urban hospital setting.

Conclusions: Psychosocial and environmental factors, including institutional racism and stigmatization, play significant roles in amplifying the burdens shouldered by racial and ethnic minority individuals with kidney disease who now also face the COVID-19 pandemic that has since turned endemic. The results of this study can inform the development of policy interventions aimed at alleviating tensions and structural conditions that impinge on kidney disease patients' wellbeing and health outcomes.

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Members of historically marginalized and underserved groups, including African Americans, Latinx, and Native Americans, among others, are disproportionately affected by chronic kidney disease (CKD) and progressive kidney failure.^{1,2} Socioeconomic and environmental factors, including exposure to institutional racism and other psychosocial stressors, play significant roles in amplifying the disease burden among these patients.^{1,3-9} Several studies have shown that social disadvantage, racial residential segregation, and exposure to environmental pollutants, all of which disproportionately affect US racial and ethnic minority populations, are associated with higher risks of death and worse kidney health outcomes.^{3,10,11} The coronavirus disease 2019 (COVID-19) pandemic brought these health inequities into even sharper focus, particularly for patients with kidney failure who faced the challenges of travel to hemodialysis units and exposure to severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) during treatment.¹²

We hypothesized that racial and ethnic minority patients with kidney failure would be affected by COVID-19

in a syndemic manner, meaning that they would suffer magnified disease burdens and overall life challenges because their kidney disease and the effects of structural racism synergistically interact with pandemic conditions to amplify each adverse condition's harmful effects.^{10,13,14} Our study advances the literature documenting the difficulties faced by patients with kidney failure in the United States^{4,6-8,15,16} and elsewhere,¹⁷⁻²⁰ by focusing explicitly on how patients with kidney failure from racial and ethnic minority groups who live in under-resourced US urban communities manage the intensified structural and psychosocial challenges during the COVID-19 pandemic (subsequently turned endemic). In this article, we describe patients' accounts of their illness and treatment experiences before and during the COVID-19 pandemic at dialysis centers and within their communities, and their perceived sources of support. Our findings could inform the development of policy interventions and regulatory agendas aimed at alleviating tensions and structural conditions that impinge on kidney disease patients' wellbeing and health outcomes.

PLAIN-LANGUAGE SUMMARY

Members of racial and ethnic minority groups in the United States experience the highest rates of progressive kidney failure and face significantly more socioeconomic and psychosocial challenges. We interviewed 20 patients who receive maintenance hemodialysis treatment from centers affiliated with a safety-net hospital. Patients described stigmatization as a central element of their life experience and the pandemic as a difficult challenge (but not a complete rupture) that added to their struggles with illness-related, race-related, and class-related stigmas. Social networks, particularly family, friends, and religious communities, are key sources of support crucial to coping with illness. Findings from this study can inform health care providers and community workers and guide the development of policy interventions to provide better support for these patients.

METHODS

Study Design, Setting, and Participant Selection

Using a qualitative study design, we conducted in-depth interviews to examine patients' experiences living with kidney failure, including the challenges and sources of support they describe. We recruited patients who were aged 18 years or older, proficient in English, and who received care through dialysis centers affiliated with Boston Medical Center (BMC). BMC is a safety-net hospital where ~60% of the patients are from racial or ethnic minority populations. Study participants were approached in person or by telephone, and each participant was interviewed separately. All study participants received a \$25 gift card as a token of gratitude for their time. The study was approved by the BMC institutional review board (#39751).

Data Collection

To elicit patients' narratives, semistructured interviews using open-ended questions were conducted by a study team of 2 researchers (M.S. and I.M.S.) with experience in qualitative study conduct and research methodology (Item S1). The interview guide was informed by the authors' previous work and literature reviews.^{4,8,10,12,15,16,21-25}

The researchers had no relationship with the participants before the interviews. Interviews were conducted between December 2020 and August 2021 by telephone or video call after ascertaining verbal consent. Using open-ended questions, participants were asked to reflect on their personal illness experience before and during the COVID-19 pandemic, any challenges they faced, and their sources of support. Participants were encouraged to elaborate on responses wherever possible. Interviews were audiotaped and transcribed verbatim. Results were discussed and evaluated in research team meetings throughout the interview collection process. Recruitment and analysis

continued until thematic saturation in the main themes was achieved.²⁶ Interviews had an average length of 73 minutes (range 35-295). Demographic characteristics were collected to provide descriptive information about participants.

Analysis

Interview transcripts were entered into NVivo version 12 1.6.1 (QSR International) and analyzed using thematic content analysis. Coding was performed by M.S., I.M.S., and N.H.N. We used line-by-line coding to inductively identify initial concepts and develop a preliminary codebook. Codes for themes and the final codebook were developed by combining or creating new themes or subthemes and decided by consensus after M.S., I.M.S., and N.H.N. independently coded the first 5 interviews. Any disagreements were resolved through iterative discussions until consensus was reached to ensure that the findings represented the full range and depth of the data. Interviews were conducted until saturation of the main constructs was reached. The diverse backgrounds of the authors (social science and medical anthropology, public health, and clinical nephrology) allowed the data to be interpreted from diverse perspectives. We adhered to the consolidated criteria for reporting qualitative research (COREQ) (Table S1).²⁷

RESULTS

The baseline characteristics of patients who participated in this study are shown in Table 1 and Table S2. Participants' mean age \pm (SD) was 57 ± 14 years; 45% were women. All had been on maintenance hemodialysis for a period of 1-21 years. Eighteen participants self-identified as Black or African American, one as Latinx, and one as Asian American. Three main themes emerged from the interviews, as follows: (1) patients' experiences of stigma and stigmatization related to race, class, and illness status; (2) patients' illness and treatment experiences before and during the COVID-19 pandemic as relatively continuous; and (3) patients' coping strategies and sources of support as entwining personal, social, and institutional dimensions. Respective subthemes are described further, and additional illustrative quotations are presented in Table 2.

Stigma and Stigmatization

Societal Racism and Racial Stigmatization

Most patients experienced racial stigmatization and racism. This included racist encounters in their personal or work environments, experiences of police brutality, and racial discrimination in the medical and health care systems. For example, patients attributed inadequate access to pain relief to medical racism: "the black male is not getting what he needs. I was going through a significant amount of pain for more months than I should be able to count" (#13, Black or African American man in his 40s).

Table 1. Demographic Characteristics of Study Participants (n = 20)

Age, y	
Mean ± SD	57 ± 14
Median age (range) y	56 (37-85)
Sex, n (%)	
Women	9 (45)
Men	11 (55)
Racial/ethnic identity, n (%)	
Black/African American	18 (90)
Latinx	1 (5)
Asian/Asian American	1 (5)
Duration of kidney disease	
Years since diagnosis (mean ± SD)	10.3 ± 5.6
Median years since diagnosis (range)	10 (1-21)
Years on dialysis (mean ± SD)	6.2 ± 5.7
Median years on dialysis (range)	5.5 (0.3-21)
History of kidney transplantation	5 (25%)
Employment status, n (%)	
Employed full-time	2 (10)
Employed part-time	0 (0)
Homemaker	0 (0)
Disabled	15 (75)
Retired	2 (10)
Unknown	1 (5)
Duration of interviews with participants, minutes	
Mean ± SD	72.8 ± 54.5
Median (range)	61.5 (35-295)

Institutional Stigmatization Related to Socioeconomic Status or Class

A minority of patients also reported feeling disrespected and stigmatized in relation to their socioeconomic status and class: “When they see people come in (to the hospital), patients come in with bags, they straight assume that they’re homeless and they got no insurance or whatever. So sometimes, the doctors or nurses assume this person’s homeless just because of what, backpacks or whatever” (#8, Black or African American man in his 40s).

Individual Stigma Related to COVID-19

Several patients who contracted COVID-19 described feeling stigmatized by public health measures that required them to receive treatment at a facility with only SARS-CoV-2 positive patients, even though this was accepted as best practice. One patient alternatively reported feeling stigmatized in his community for being cautious and following public health guidelines: “I went into stores, and they talk [behind my back] ’cause I had the mask on. I had my mask and my gloves on” (#7, Black or African American man in his 50s).

Structural and Self-Stigma Related to Kidney Disease

Patients did not associate dialysis itself with stigma related to the weekly trips that precluded isolation and left them

potentially more vulnerable to contract SARS-CoV-2 or serve as disease vectors, but they did face a range of stigmas related to their illness. Stigmas included self-blame or feeling blamed by others for a potentially unhealthy lifestyle [“I’ve got kidney disease because of high blood pressure and not really drinking water because I didn’t [...] take time to just learn about my health and what I should do” (#14, Black or African American man in his 50s), and for their struggles to hold a steady full-time job. For example, a former preschool teacher lamented leaving her beloved job because of “feeling sick all the time,” and the inability to “get down on the floor with the kids and interact with them” (#3, Black or African American woman in her 50s). Several men also bemoaned their diminished sex drive, financial struggles because social security benefits inadequately replace their former income, and differential treatment from friends and kin who worry over their health (Table 2). One patient protested in frustration, “How do you get a job when you’re so tired from dialysis? That’s what I told the social worker! [...] She couldn’t help me” (#7, Black or African American man in his 50s).

Pandemic-Related Ruptures and Continuities Continuities and Changes in Experience With Health Care and Medical Providers

Most patients noted that their weekly dialysis treatment provided a form of structure and continuity in a time otherwise characterized by rupture and crisis. Several patients also said they did not feel that they were treated differently by staff and health care professionals in dialysis centers and even applauded improved hygiene [“they’re more clean and, [...] keep everything sterilized” (#4, Black or African American woman in her 60s)], but expressed concern because of high staff turnover in dialysis facilities. One patient complained that the quality of care had never been good at Boston’s teaching hospitals: “some of them are young, they’re bringing a whole lot of trainees. They use you for a guinea pig, you know what I mean. [...] They prick you 4 to 5 times, they’re probably learning, you know” (#19, Black or African American man in his 60s).

A few patients noted that their access to health care through telehealth or outside of dialysis was delayed or became more difficult: “In the course of the beginning of COVID, my eyesight started failing, my kidneys started going, and also, I had an issue with hidradenitis suppurativa. [...] I’m just getting treatment now, because of COVID, and not being able to see my dermatologist as much as I needed to in order to get the best care that I could” (#13, Black or African American man in his 40s).

Continuities and Disruptions in Dialysis Center Camaraderie

Several patients pointed to pandemic-related disruptions to their sense of community at dialysis facilities: “All we do is go there, get our treatment, and come back home. You

Table 2. Themes and Subthemes With Illustrative Quotes

Stigma and Stigmatization	
Societal racism and racial stigmatization	<p>“People out there are very, I don’t know how to explain to you, it’s like, outwardly racist. [...] I work amongst a lot of white people, you know, white people don’t say, “Hi” to me, head down all day, every day [...] You got to learn to live with it, or you got to be crazy. [...] this skin color, it’s not a death sentence, but it definitely holds a lot of weight on it.” (#16, Black or African American man in his 30s, working intermittently)</p> <p>“I think [racism] got worse, people showed their true color when Trump became president, that’s what I always said. Because sometimes even if people are prejudiced, they can keep it to themselves, they don’t really want to show you that they don’t like you. But since Trump became president, everybody’s like, “Oh, now we are free, we can be whoever we want.” All those things going on, [it’s] very hurtful, especially when black people get killed by a cop, then it’s very tough.” (#18, Black or African American woman in her 50s)</p> <p>“I’ve been on the [transplant] list for about 3 or 4 years. [...] They might slip other [White patients] in there and black people end up never getting [a transplant]. And that’s why we end up dying and they’re living.” (#19, Black or African American man in his 60s)</p>
Institutional stigmatization related to socioeconomic status or class	<p>Now that I’m not working, I have MassHealth, and having MassHealth, it’s really no help. [...] There’s certain hospitals you could go to, they’ll do the basic, but if it’s anything major, if you don’t have good insurance—you’re on your own. (#12, Black or African American man in his 60s)</p> <p>Referring to health care professionals: “what I am going to be able to do is have you respect me. And I can’t do that if I’m poor, which is where the money part comes in, right? [...] I also know when I’m being talked to in a condescending way.” (#13, Black or African American man in his 40s, working full-time)</p>
Individual stigma related to COVID-19	<p>“I went into stores, and [people] talked [behind my back] because I had the mask on. I had my mask and my gloves on.” (#7, Black or African American man in his 50s)</p> <p>“People, a lot of people were scared of me too. They don’t want to get in contact with me. They don’t want to get close to me because of the COVID.” (#17, Asian American man in his 60s)</p>
Structural and self-stigma related to kidney disease	<p>“Since I’ve been on dialysis, it curbs your sex drive—real bad. [...] [people]’ve got to be more careful around me, what they say and how they treat me. I’m like, well, just do what you normally do. [...] And] financially it’s been kind of rough. [...] I get my retirement and social security, but –it doesn’t measure up to be what I used to make when I was working. So, being on a fixed income, it makes it really kind of rough for me. [...] the amount I’m getting now, I can barely pay all of my bills.” (#12, Black or African American man in his 60s)</p> <p>Referring to dialysis-related weight loss: “I used to be 235 pounds, and when everyone saw me, I don’t know, they thought I was smoking crack or what.” (#1, Black or African American man in his 50s)</p>
Pandemic-related ruptures and continuities	
Continuities and changes in experience with health care and medical providers	<p>“I feel concern because the staff seems to be leaving, and new people are coming in all of the time. [...] Recently there’s been a lot of turn over.” (#10, retired, Black/African American woman in her 80s)</p> <p>Referring to telehealth: “I never paid enough attention to cell phones, so there were a lot of things I cannot do on cell phone. And then now, you have to deal with it, everything you have to do [you need] the cell phone to do it. If you need to make an appointment, you have to go online. So, it was kind of hard.” (#20, Black or African American woman in her 70s)</p> <p>Patient who was hospitalized at the beginning of the COVID-19 pandemic: “I was in the hospital, it was very mentally exhausting—[...] I don’t think many people would be able to understand, these are different circumstances with COVID. I couldn’t have any visitors. I was by myself.” (#9, Black or African American man in his 30s, working full-time)</p>
Continuities and disruptions in dialysis center camaraderie	<p>“The atmosphere [in the dialysis center] is totally different from what it was at the beginning. We don’t sit and talk like we used to because of the 6 feet distance, [we’re] apart from each other. [...] We have to keep our face covering, our mask, on. Before all this happened, we all just sit around and get together in the waiting room and have our cup of coffee, and sit and talk, and just enjoy the morning. But now, it’s a distance.” (#2, retired, Black or African American woman in her 60s)</p>

(Continued)

Table 2 (Cont'd). Themes and Subthemes With Illustrative Quotes

Stigma and Stigmatization	
Adherence to public health guidelines	<p>“I go out, but I make sure I have a mask on. I constantly use sanitizers. I always keep my keychain with the sanitizer on it and refill the bottle up.” (#14, Black or African American man in his 50s)</p> <p>“I’m fully vaccinated. I’m on the ball with that.” (#15, Black or African American woman in her 40s whose work/disability status remained vague)</p>
Coping strategies and sources of support	
Support from social network	<p>“My cousin, me and her, she always, we always talk to each other. Like, every other day. [...] She always checks up to see if I need anything or you know, help with something. And this was before, uh, COVID, even just the fact that I’m on dialysis, so she always asks if I need help with anything.” (#5, Latina woman in her 40s)</p> <p>“[My wife] tells me, well, you need to start taking your medication [...] because some mornings if I don’t eat, I don’t take my medication because if I take it I get nauseous] so for the most part, [my wife] stays right on top of it.” (#12, Black or African American man in his 60s)</p> <p>“I have good family members, even when they are going through hard times, if I’m in need of something, they always make sure, I that I get it because they know that I get depressed very easily. [...] They just want to ease my pain.” (#18, Black or African American woman in her 50s)</p>
Religion, faith, and spirituality	<p>“I’m a believer in God so you know I just ask God to give me the strength. Keep going and do what I have to do. [...] I was still a little afraid of having to go to dialysis with the COVID going on. Like I said I prayed about it.” (#20, Black/African American woman in her 70s)</p> <p>“You have to pray; I have strong faith and so that helped me a lot sometimes. You just go on YouTube, you put the music on, and then you listen to those, I’m a Christian, so that helps you mentally a little bit. [...] I went through a lot of trouble and then at the same time, God lifts me up and gets me out of all of those troubles [...]” (#18, Black or African American woman in her 50s)</p>
Self-efficacy and caregiving	<p>“I do cook for my boys. [...] They work during the day and I’m home by myself during the day. So, when they get off work or whatever, they’ll go to the store and pick something up for me.” (#3, Black/African American woman in her 50s)</p> <p>“I look out for my son the best that I can, and I watch him.” (#1, Black or African American man in his 50s)</p>

^aWe indicate brief segments of omitted text with bracketed ellipses (...) and text added for clarity with brackets ([text]).

can’t do nothing in there no more, we used to go and have a little thing for lunch, but you can’t eat nothing cause of coronavirus” (#4, Black or African American woman in her 60s). However, patients also said that the shared feeling of being more vulnerable and at risk for more severe disease, begun before the pandemic, contributed to their sense of support and continued shared camaraderie: “We’ll talk in the waiting room, or they’ll come to my chair and talk to me until they get put on. They talk to me and tell me what they’re feeling, and what they want to complain about” (#3, Black or African American woman in her 50s).

Adherence to Public Health Guidelines

Almost all patients adhered to some, if not all, clinical recommendations, such as wearing masks, washing hands, using sanitizers, or wearing gloves, but rejected complete social isolation [“I go out, but I make sure I have a mask on. I constantly use sanitizers. I always keep my keychain with the sanitizer on it and refill the bottle up” (#14, Black or African American man in his 50s)]. With few exceptions, patients took or were ready to take the COVID-19 vaccine after clinical recommendations.

Coping Strategies and Sources of Support **Support From Social Network**

A key source of support for most patients is the social network composed of family and extended family members and friends. Almost all patients mentioned how their kin and friends helped them with daily tasks such as cleaning, going shopping, bringing food, and calling them. As one patient described, “I live with my daughter. She’s helping taking care of me. Ever since I’ve been sick, she’s been helping me. Without her, I think I’d probably be dead” (#14, Black or African American man in his 50s). Another patient noted, “my oldest son he’s like my caretaker. So, he comes visit me all the time. He comes during the week if I need something he’ll go get it [...]. He’s the person that really helps me out” (#20, Black or African American woman in her 70s). Conversely, those who had lost kin expressed high levels of psychosocial distress, as exemplified by a patient who told us, sniffing, of his struggles after losing his mother and brother to dialysis: “Sometimes, uhm, I get very emotional ‘cause it’s just—it’s getting too much. And I just want to die, sometimes” (#8, Black or African American man in his 40s).

Similarly, although those without supportive kin gratefully described a helpful social worker or advocate [“I got my health care proxy, [...] she’s been trying to help me and she ain’t even my family” (#19, Black or African American man in his 60s)], they also were most likely to describe housing insecurity [“when I got out of isolation [from COVID], I lived with my cousin for a couple weeks, then I walked home to my mother’s house [...], and then me and her dad had a fight, and [...] I was homeless for a couple months” (#8, Black or African American man in his 40s)].

Religion, Faith, and Spirituality

Almost all patients described prayer, faith, or their church community as crucial to coping with chronic illness and social isolation before and during the pandemic. As one patient described it, “I pray. I pray a lot. And I have a lot of faith. So that gets me up and going” (#6, Black or African American woman in her 50s). Patients also alluded to other ways in which religion or spirituality has been supportive, including coping with systemic societal ills. One patient noted, contrasting his church with the racism he faced in broader society: “We have all kinds of different nationalities in church. So, there’s really no room for racism. There’s just an abundance of respect for people as people, respecting their cultures, where they come from, and where they are in their Christian journey” (#9, Black or African American man in his 30s).

Self-Efficacy and Caregiving

Finally, most patients saw caregiving as an important coping mechanism and said that they maintained close relationships with select relatives and friends even before the COVID-19 vaccine rollout. In particular, women who participated in this study also described how they helped their children and grandchildren, whom they babysat while the youngsters’ parents went out to work: “I have 4 godkids. So, they really keep my day up, they keep my time occupied. I babysit them every weekend” (#2, Black or African American woman in her 60s).

DISCUSSION

Though portrayed in the public media as a societal-wide rupture, the pandemic figured in the accounts of patients receiving hemodialysis more as a *difficult challenge* that exacerbated their sense of vulnerability and added to their longer-term struggles with illness-related, race-related, and class-related stigmas. When asked about their sources of support, patients in this study highlighted crucial social networks that helped them cope. Among these, family members usually figure most prominently, followed by friends and their church communities. Patients without supportive kin described the highest levels of psychosocial stress and housing insecurity.

Overwhelmingly, patients expressed a willingness and desire to adhere to medical recommendations, such as

masking, vaccination, regular dialysis treatment, and dietary changes, to prevent further deterioration in their health. Cutting off social relations in compliance with social distancing mandates, however, was not an option for any patient. Also, with the inability to work because of their illness and the demanding thrice-weekly dialysis schedule, many patients alluded to struggling financially. However, most patients praised or said they had no complaints about the care they received, and most reported enjoying reliable, free transport to their dialysis center.

Our findings that stigma and stigmatization constitute important elements of kidney disease patients’ illness experiences are consistent with previous studies in other disease settings.²⁸⁻³³ Studies in patients with non-communicable diseases such as diabetes,^{29,30} respiratory diseases,³⁴ or epilepsy²⁸ also describe how stigmatization aggravates a sense of isolation and despair. Another study of Māori patients with CKD found that they experience marginalization in the New Zealand health care system, which leads to delayed diagnosis, fear of dialysis treatment, and increased psychosocial stress. Furthermore, Māori patients reported that a focus on individuals rather than family resulted in their diminished engagement and did not align with their priorities.³⁵ Our study, too, not only points to the relevance of directing care beyond the patient-doctor dyad but suggests a broader implication: that personal, familial, social, and institutional supports are key to coping with progressive kidney failure and likely best work together to overcome the harmful effects of stigmatization.

Patients did not offer specific solutions to their woes, but we infer, based on our findings and previous global health research,^{14,17,19,36,37} that both a more robust health care system that would guarantee the detection and prevention of the precursors to kidney disease and more systemic institutional and cultural change are needed to eliminate the ongoing health burdens imposed by overt and covert racism in patients’ daily lives. In addition, greater coordination between interdisciplinary health care and service providers, and with patients’ kin or other social sources of support, including spiritual communities, could assist in building trust, alleviating historic ethnic or race and class inequities, and improving health outcomes.

Our study has several limitations. Because we interviewed patients from dialysis centers affiliated with a single safety-net urban hospital in Boston, Massachusetts, our findings may not be applicable to other settings or regions of the country. It is also possible that only healthier patients volunteered to participate in our study or that social desirability bias may have led some study participants to censor negative views or experiences they have had in their clinical encounters.

In conclusion, economically disadvantaged, racial and ethnic minority patients with kidney failure faced amplified disease and psychosocial burdens during the COVID-19 pandemic that challenged their longstanding efforts to live dignified lives in the face of racism, class, and illness-

related stigmas. Helpful kin and friends, faith-based practices and organizations, and the routines of dialysis helped mitigate some difficulties. Although dialysis is covered by Medicare, Medicaid, and MassHealth, coordination between interdisciplinary teams of health care and service providers, such as clinical specialists, nurse practitioners, dialysis technicians, social workers, and dietitians, could be challenging and became more difficult during the pandemic. In addition, we suggest, based on patients' identification of their social supports, that facilitating such interdisciplinary clinical collaboration could even more effectively improve patients' lives if it also partnered with patients' social networks to ensure continuous care and support. We caution, however, based on our experience and patients' narratives, that until and unless the broader societal ills of structural racism and resource inequities are overcome, chronic, serious illnesses like kidney failure, which disproportionately afflict racial and ethnic minority groups and under-resourced communities, will continue to take heavy tolls on patients, their social networks, and the health care system as a whole.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Item S1. Participant interview guide

Table S1. COREQ 32-Item Checklist.

Table S2. Individual Description of Study Participants.

ARTICLE INFORMATION

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REFERENCES

1. Tarver-Carr ME, Powe NR, Eberhardt MS, et al. Excess risk of chronic kidney disease among African-American versus white subjects in the United States: a population-based study of potential explanatory factors. *J Am Soc Nephrol.* 2002;13(9):2363-2370.
2. Saran R, Robinson B, Abbott KC, et al. US renal data system 2019 annual data report: epidemiology of kidney disease in the United States. *Am J Kidney Dis.* 2020;75(11)(suppl 1):A6-A7.
3. Norton JM, Moxey-Mims MM, Eggers PW, et al. Social determinants of racial disparities in CKD. *J Am Soc Nephrol.* 2016;27(9):2576-2595.
4. Crews DC, Charles RF, Evans MK, Zonderman AB, Powe NR. Poverty, race, and CKD in a racially and socioeconomically diverse urban population. *Am J Kidney Dis.* 2010;55(6):992-1000.
5. Crews DC, Gutiérrez OM, Fedewa SA, et al. Low income, community poverty and risk of end stage renal disease. *BMC Nephrol.* 2014;15:192.
6. Crews DC, Novick TK. Social determinants of CKD Hotspots. *Semin Nephrol.* 2019;39(3):256-262.
7. Johns TS, Estrella MM, Crews DC, et al. Neighborhood socioeconomic status, race, and mortality in young adult dialysis patients. *J Am Soc Nephrol.* 2014;25(11):2649-2657.
8. Cervantes L, Hasnain-Wynia R, Steiner JF, Chonchol M, Fischer S. Patient navigation: addressing social challenges in dialysis patients. *Am J Kidney Dis.* 2020;76(1):121-129.
9. Mehrotra R, Soohoo M, Rivara MB, et al. Racial and ethnic disparities in use of and outcomes with home dialysis in the United States. *J Am Soc Nephrol.* 2016;27(7):2123-2134.

10. Crews DC, Purnell TS. COVID-19, Racism, and racial disparities in kidney disease: galvanizing the kidney community response. *J Am Soc Nephrol*. 2020;31(8):1-3.
11. Scammell MK, Sennett CM, Petropoulos ZE, Kamal J, Kaufman JS. Environmental and occupational exposures in kidney disease. *Semin Nephrol*. 2019;39(3):230-243.
12. Novick TK, Rizzolo K, Cervantes L. COVID-19 and kidney disease disparities in the United States. *Adv Chronic Kidney Dis*. 2020;27(5):427-433.
13. Singer M. Syndemics. In: Cockerham WC, Dingwall R, Quah SR, eds. *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society*. 1st ed. Wiley-Blackwell; 2014: 2419-2423.
14. Singer M, Bulled N, Ostrach B, Mendenhall E. Syndemics and the biosocial conception of health. *Lancet*. 2017;389(10072): 941-950.
15. Sharp LA. *Strange Harvest: Organ Transplants, Denatured Bodies, and the Transformed Self*. University of California Press; 2006.
16. Kaufman SR. *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*. Duke University Press; 2015.
17. Hamdy SF. When the state and your kidneys fail: political etiologies in an Egyptian dialysis ward. *Am Ethnol*. 2008;35(4): 553-569.
18. Crowley-Matoka M. Anthropological issues in renal care. *Kidney Int Suppl*. 2013;3(2):219-222.
19. Crowley-Matoka M. *Domesticating Organ Transplant: Familial Sacrifice and National Aspiration in Mexico*. Duke University Press; 2016.
20. Kierans C. Anthropology, organ transplantation and the immune system: resituating commodity and gift exchange. *Soc Sci Med*. 2011;73(10):1469-1476.
21. Russ AJ, Shim JK, Kaufman SR. 'Is there life on dialysis?': time and aging in a clinically sustained existence. *Med Anthropol*. 2005;24(4):297-324.
22. Shohet M. Beyond the clinic? Eluding a medical diagnosis of anorexia through narrative. *Transcult Psychiatry*. 2018;55(4): 495-515.
23. Shohet M. *Silence and Sacrifice: Family Stories of Care and the Limits of Love in Vietnam*. University of California Press; 2021.
24. Schmidt IM, Waikar SS. Separate and unequal: race-based algorithms and implications for nephrology. *J Am Soc Nephrol*. 2021;32(3):529-533.
25. Schmidt IM, Shohet M, Serrano M, et al. Patients' perspectives on race and the use of race-based algorithms in clinical decision-making: a qualitative study. *J Gen Intern Med*. 2023;38(9):2045-2051.
26. Hamberg K, Johansson E, Lindgren G, Westman G. Scientific rigour in qualitative research—examples from a study of women's health in family practice. *Fam Pract*. 1994;11(2): 176-181.
27. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357.
28. Ablon J. The nature of stigma and medical conditions. *Epilepsy Behav*. 2002;3(6S2):2-9.
29. Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open*. 2013;3(11):e003384.
30. Browne JL, Ventura AD, Mosely K, Speight J. Measuring the stigma surrounding type 2 diabetes: development and validation of the type 2 diabetes stigma assessment scale (DSAS-2). *Diabetes Care*. 2016;39(12):2141-2148.
31. Earnshaw VA, Quinn DM, Kalichman SC, Park CL. Development and psychometric evaluation of the Chronic Illness Anticipated Stigma Scale. *J Behav Med*. 2013;36(3):270-282.
32. Jackson JE. Stigma, liminality, and chronic pain: mind-body borderlands. *Am Ethnol*. 2005;32(3):332-353.
33. Link B, Phelan J. Conceptualizing stigma. *Annual Review Of Sociology*. 2001;27:363-385.
34. Rose S, Paul C, Boyes A, Kelly B, Roach D. Stigma-related experiences in non-communicable respiratory diseases: A systematic review. *Chron Respir Dis*. 2017;14(3):199-216.
35. Walker RC, Walker S, Morton RL, Tong A, Howard K, Palmer SC. Maori patients' experiences and perspectives of chronic kidney disease: a New Zealand qualitative interview study. *BMJ Open*. 2017;7(1):e013829.
36. Moran-Thomas A. Struggles for maintenance: patient activism and dialysis dilemmas amidst a global diabetes epidemic. *Glob Public Health*. 2019;14(6-7):1044-1057.
37. Farmer P. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. University of California Press; 2004.