Barriers and Facilitators to Staying on Peritoneal Dialysis from the Perspective of Black and Latino Patients with Kidney Failure – A Qualitative Study

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Abstract

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Introduction: Despite being associated with better quality of life, lower cost, and longer preservation of residual kidney function compared to hemodialysis (HD), peritoneal dialysis (PD) is underutilized for Black and Latino patients with kidney failure. The objective of this study was to identify barriers and facilitators to dialysis retention among Black and Latino patients with kidney failure.

Methods: We conducted a qualitative study using in-depth, semi-structured interviews of adult Black and Latino patients currently on PD. Interviews were conducted in English and Spanish, transcribed verbatim, and analyzed using constant comparison method,[1] guided by Andersen's behavioral model for health services use.[2]

Results: Our sample consisted of 2 Black English-speaking and 7 Latino Spanish-speaking participants (mean age 48 years, 6 female, mean duration on PD 38 months). Facilitators to PD retention included positive attitudes towards PD, self-efficacy to perform dialysis at home, access to a supportive and readily available dialysis team, and family support. Barriers to PD retention included lack of Spanish-speaking dialysis providers, and underuse of professional medical interpreters for Spanish-speaking participants. The initiation of PD was noted to have a negative impact on mental health and mobility and required unanticipated adaptation to both work and social schedules for patients and their caregivers. Despite reporting PD-associated complications and symptoms, almost all participants reported an overall positive change in their health and quality of life since starting PD. All participants reported that they would still choose PD over other dialysis modalities if given the choice.

Conclusions: Provision of high-quality language assistance services or bilingual providers and preparation for transitioning to home PD may improve patient experience and PD retention. This work leverages patient experience to identify areas for future interventions aimed at addressing the equity gap in home dialysis for Black and Latino patients with kidney failure.

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Introduction

In 2020, the prevalence of kidney failure was almost 4.3 times higher among Black patients and almost 2.3 times higher among Hispanic or Latino patients compared to White individuals.[3] Not only are Black and Latino patients disproportionately affected by kidney failure, they also encounter disparities in treatment.[4,5] Treatment options for patients with kidney failure include dialysis and kidney transplantation.[6] The most common dialysis modalities are hemodialysis (HD) and peritoneal dialysis (PD).[6] HD is normally performed at a dialysis center several times a week, while PD can be performed in the comfort of home, most commonly daily.[6] PD is associated with lower risk of hospitalizations, lower healthcare costs, slower decline in residual kidney function, and better health-related quality of life compared to HD,[7-11] yet this dialysis modality is underutilized for Black and Latino patients with kidney failure.[4,5] Furthermore, Black patients stop PD and convert to center-based HD at a higher rate than White patients.[5,12,13]

The barriers to the use of PD at dialysis initiation among the general population of patients with kidney failure have been well documented and include lack of home space for equipment, lack of social support, and no prior kidney disease education.[14,15] What is less understood are the factors that prevent Black and Latino patients from initiating PD and lead them to stop PD to change to in-center HD. Identification of barriers to PD retention can inform interventions at the health system-level to address the equity gap in the treatment of kidney failure among minoritized patients.

To address this gap, we designed a qualitative research study using in-depth, semi-structured interviews with Black and Latino patients to understand the factors that may shape Black and Latino patients' decision to stop PD and transfer to in-center HD. This study examined barriers and facilitators to retention of PD from the perspective of Black and Latino patients with kidney failure who are currently on PD at home.

Methods

Study design

This is a qualitative study with in-depth, semi-structured interviews. Study procedures were approved by the University of Washington Institutional Review Board.

Recruitment and data collection

The inclusion criteria were adult (18 years old and older) English- and Spanish-speaking Black and Latino patients who have been receiving PD for at least 3 months. Patients who had stopped PD because they received a kidney transplant were excluded. Participants were recruited from a regional non-profit, community-based dialysis organization and an academic medical center that provides specialized care for patients with kidney failure. Potential participants were referred by nephrologists and/or identified through an electronic database of patients who are currently receiving PD. Participants were screened for eligibility using electronic health records.

Interview guide was informed by literature on barriers to initiating PD in the general population of patients with kidney failure, input from a patient advisory committee, and Andersen's behavioral model of health service use.[2] Under this model, utilization of healthcare services is determined by societal, health services system, and individual (predisposing, enabling, and need for care) factors.[2] Predisposing factors include demographic variables, and attitudes and beliefs towards health services. Enabling factors include individual, family, and structural resources. Lastly, need for care includes objective and perceived illness.[2] The semi-structured interview included open-ended questions about participant experience with PD, caregivers' and family's experience with PD, challenges to performing PD at home, and resources or support that would have facilitated continuing with PD (Supplemental Table 1).

Recruitment was performed over the phone and informed consent was obtained in the participant's preferred language (English or Spanish). Phone interviews were conducted in English and Spanish by a bilingual, multicultural researcher (ES) from 7/18/22 to 1/16/2023 and lasted approximately 30-45 minutes. Interviews were audio-recorded and transcribed verbatim. Demographic information was collected via a researcher-administered telephone survey. Using open ended questions, participants were asked what gender, race, and ethnicity they identified with. They were also asked questions about income, educational attainment, housing stability and distance to dialysis center.

Data analysis

Analysis was conducted using thematic analysis methodology by Miles, Huberman, and Saldaña.[1] Two coders (ES, JB) created a tentative codebook using the interview guide. The codebook captured the domains under the Andersen Behavioral Model.[2] The codebook was used to conduct deductive coding to tentatively identify codes that capture examples of the domains. To capture discussions that emerge beyond the a priori questions, we used inductive, constant comparison approach, in which concepts were identified and themes derived from interview data. Using an iterative process, the coders met bimonthly to refine the codebook, adding, removing, and revising codes as needed to address inter-rater agreement and to compare new data with existing data. We built consensus around themes that are identified throughout the coding and analysis process. We compared the themes arising from the data and determined possible linkages across participants and thematic categories. The data were organized and coded using Dedoose version 9.0.86.[16] Transcripts were individually coded in the same language as the interview, either English or Spanish, by two bilingual researchers (ES, JB). Interview transcripts were analyzed as they became available to assess for thematic saturation and further refine interview guide questions and codebook.

Illustrative quotes that were originally in Spanish were translated to English by one bilingual researcher (ES) and verified by a second bilingual researcher (JB) (Supplemental Table 2). Any discrepancies in translation were discussed until consensus was reached.

Results

Participant Characteristics

Twelve patients were approached for participation in this study, of which 3 declined to participate. Reasons for declining participation included limited time and lack of interest (Figure 1). Our final sample consisted of 9 participants (2 Black, 7 Latino, 6 female, mean age 48 years). Mean time on PD was 38 months. The most common type of insurance was Medicaid (Table 1). One participant did not complete the demographic survey.

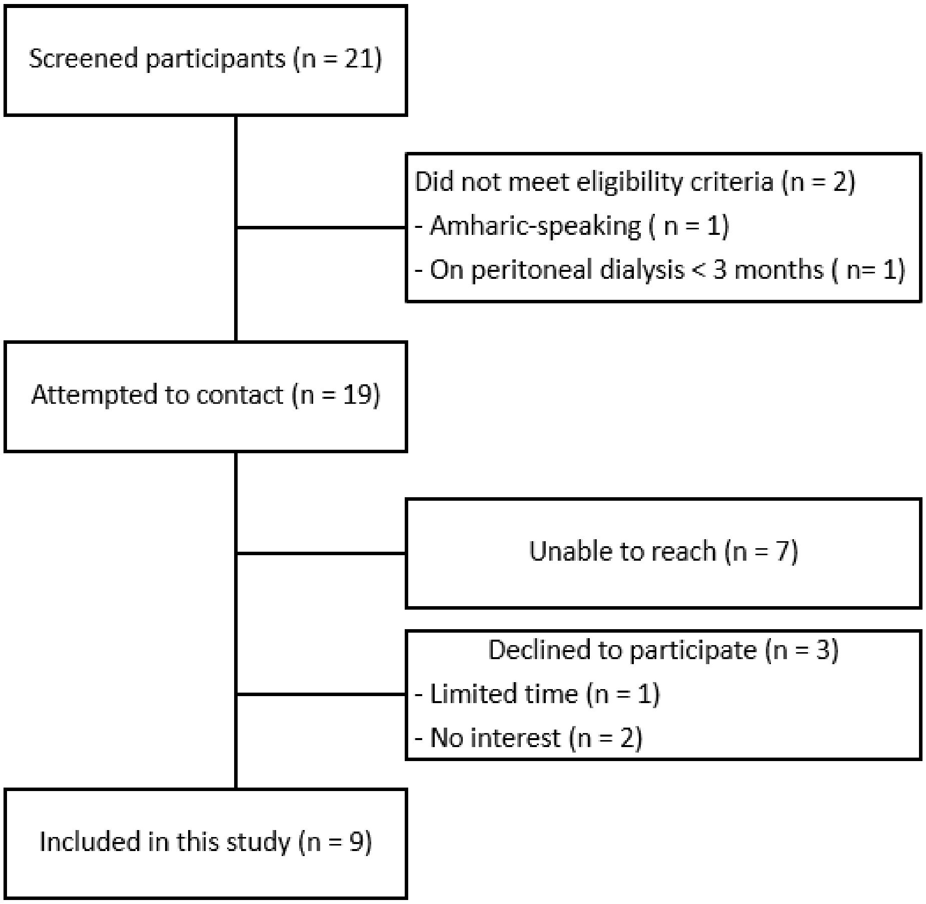


Figure 1. Participant selection flow diagram

Table 1. Patient-reported sociodemographic and clinical characteristics of study participants (N = 9)

Characteristic	n (%)
Age – mean (SD) years	48 (12)
Sex	
Male	3 (33)
Female	6 (67)
Gender	
Men	3 (33)
Women	5 (56)
Missing	1 (11)

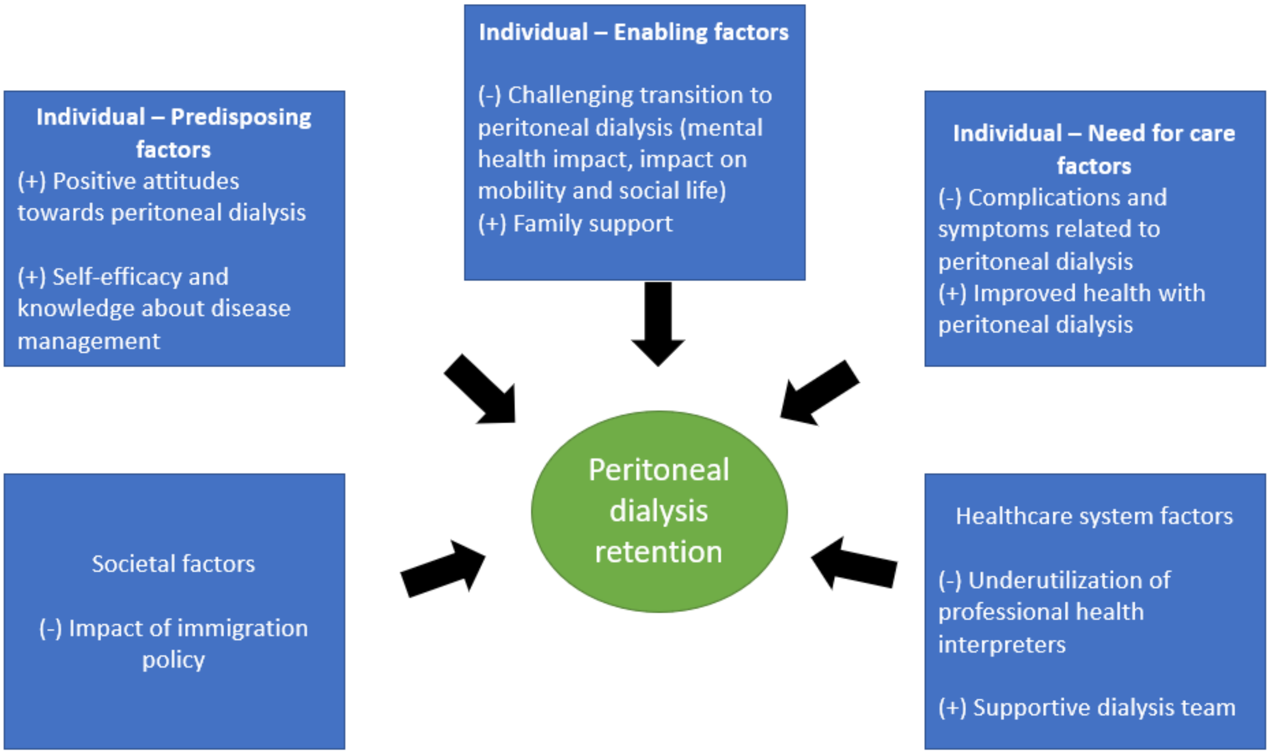
Race/Ethnicity	
Black	2 (22)
Latino	7 (78)
Highest level of completed education	
Less than high school	4 (44)
Some high school or high school graduate	2 (22)
Some college or college graduate	1 (11)
Technical/Vocational School	1 (11)
Missing	1 (11)
Household Income**	
Below federal poverty level	2 (22)
Above federal poverty level	5 (56)
Unknown or missing	2 (22)
Insurance	
Medicaid	5 (56)
Dual Medicaid/Private	4 (44)
Housing instability	0 (0)
Etiology of kidney disease	
Diabetic nephropathy	4 (44)
Hypertensive nephropathy	2 (22)
Other*	3 (33)
Duration on PD	
Mean (SD) months	38 (20)
Range	8 – 72
Home distance to dialysis center in minutes – mean (SD)	23 (16)
Missing	1 (11)

*Note: Other includes lupus nephritis, microscopic polyangiitis, and anti-Glomerular Basement Membrane disease

**Participants were asked about household annual income and the number of persons living in the household. This information was used to determine if a household income fell below the federal poverty level based on the Department of Health and Human Services Poverty Guidelines for 2023.[17]

Themes from Qualitative Interviews

We identified 9 themes. Within the predisposing factors domain, positive attitudes towards dialysis and self-efficacy to perform PD at home emerged as facilitators. Within the enabling factors domain, challenging transition to PD emerged as a barrier while family support emerged as a facilitator. Among the need for care factors, complications and symptoms related to PD was identified as a barrier while improved health with PD served as a facilitator. Among healthcare system factors, underutilization of professional health interpreters emerged as a barrier and support from the dialysis team emerged as a facilitator. Lastly, impact of immigration policy was identified as a barrier within the societal factors domain. Figure 2 below illustrates these themes. Starting with the individual predisposing factors in the left upper corner of the figure and moving clockwise, we discuss each below following Andersen's model of health services use.[2]



Individual – Predisposing factors

(+) Positive attitudes towards peritoneal dialysis

(+) Self-efficacy and knowledge about disease management

Individual – Enabling factors

(-) Challenging transition to peritoneal dialysis (mental health impact, impact on mobility and social life)

(+) Family support

Individual – Need for care factors

(-) Complications and symptoms related to peritoneal dialysis

(+) Improved health with peritoneal dialysis

Healthcare system factors

(-) Underutilization of professional health interpreters

(+) Supportive dialysis team

Societal factors

(-) Impact of immigration policy

Figure 2. Factors that influence peritoneal dialysis retention among Black and Latino patients with kidney failure. Barriers are denoted with the (-) sign and facilitators with the (+) sign.

Individual – Predisposing factors

1. Positive attitudes towards PD

Positive attitudes towards PD and self-efficacy to manage their illness and perform PD at home were noted as facilitators to staying on this dialysis modality. Participants generally believed that PD was helping prolong their lives and/or improve their quality of life. One participant shared, “thanks to God and thanks to this machine I am alive” (P03). When confronted with pessimistic comments from acquaintances, this participant response was “My machine is the best friend I have in the world right now” (P03).

Participants shared different reasons why they decided to choose PD over other modalities. One participant shared “then, when they told me about peritoneal [dialysis], that it would be at home, that they would train me, that they would provide a class and everything, without thinking twice I said, ‘I want the peritoneal one’” (P07). Another participant said, “they tell me that I can live a normal life, that I can eat anything I want, with moderation, right. Then I said, ‘I want the peritoneal one, I want to undergo the peritoneal one’” (P04). A family members’ positive perception of PD also influenced a participant’s choice for this modality. He explained, “that's another reason why I got PD, 'cause [my mother] insisted. When I got sick, she's like ‘PD has gotten better now and you don't have to go to a center, all that can be done at home.’” (P06).

2. Self-efficacy to perform PD at home

A few participants were initially hesitant about their own ability to perform PD at home. However, all participants felt that the training provided by their dialysis team prepared them well to independently perform dialysis. One participant reported that in her class, she was taught “how to do it manually and then how to do it with the machine, and I have mastered them both!

So, it’s just… I don’t have to follow instructions. I just do it” (P01). She further explained, “I just could not believe that all those months that I had been scared to go [to PD training], that it has been so easy. It was literally like nothing. It was just unreal” (P01). Other participants reported that their confidence in their ability to perform PD improved after the training. One participant shared, “At first, I looked at it as impossible, I was practically unsure if I was going to learn it well. But later, when the process was finished and everything, I still felt a little afraid, but deep inside, I felt that I could do it” (P02). “PD is easy. I would tell people ‘don’t be afraid’, ‘cause I was afraid at first. Yeah, now I can do it easily… after I got training, then I believe I can do it,” reported another participant (P06). Similarly, another participant described, “It seemed difficult at first, but when you learn everything, you say ‘no, it's okay, it’s nothing.’ The truth is, no, no, it hasn't been complicated for me” (P03). This participant felt so comfortable performing PD that she described herself as her own nurse.

Individual – Enabling factors

3. Challenging transition to PD

Participants described a challenging transition from not needing dialysis to initiating PD. This transition was often characterized by a negative impact on mental health, mobility, and social life. One participant described the news that she would need dialysis as a “bucket of cold water,” a saying that means receiving bad, unexpected news: “It was something completely new. It was something that I had never thought about if one day it was going to happen or if someday I was going to need it. It was practically like a bucket of water that fell on me, a bucket of cold water, on me and my family” (P02). Fear and depressive symptoms were described by several participants. “I got kind of depressed because I had seen my mom start dialysis now what, 30 years ago. I knew you needed to take a lot of care. I was scared of many things… you could get, you could get your site infected” (P06). Another participant described, “When they told me, ‘you're going to do dialysis’, and you know all the bad comments people make. For me, it was like ‘I don't want to do it, I don't want to be there, I don't want to have that done to me.’ I cried a lot the first day that I already had my tube and they took me to, well, to classes and to see how I was going to start dialysis, I also cried” (P05). Crying was a shared experience among participants: “It was very hard, I'm not going to lie to you, that is, since they told you ‘you're going to go on dialysis.’ I have always been a very active person, so when they told me ‘you are going to do this,’ I say ‘wow.’ I felt a very difficult outlook. But then I said, ‘ok I can't cry.’ I mean, I did cry, of course, but I can't spend life crying, I can't spend life complaining” (P03).

One participant who briefly received in-center HD prior to starting PD explained the way he felt: “I used to get very sad when I went to do chest HD at the dialysis center. It depresses me a lot and I felt that, every day I cried there in the dialysis center. And I said to myself, ‘this is not going to work, this, I am not going to put up with this,’ because I saw many sick people. And I said, ‘That is my destiny.’ And my morale dropped, my self-esteem dropped, everything dropped. And I said ‘no, I don't want to be like this.’” (P04). Another participant shared a similar sentiment: “When I would go up there to the place and I would see people on those machines, they looked unhappy. They were, you know like… no one was there with them, no support, no family” (P01).

Given the negative impact that starting PD had on participants’ mental health, one individual suggested, “I think that it would be good to have, I don't know if a psychologist or a therapist, who is taking you through your transition from being without anything to doing dialysis. Because I do think that many people are defeated at this time, when you say they are going to give you dialysis and you think that you will no longer be good for anything... But when you start to do dialysis, you see your change that instead of feeling tired you feel better. So now, it's like you no longer need the person who is helping you psychologically, because you already see that what they are doing to you is helping you instead of harming you" (P05).

Participants also described the emotional toll that starting PD took on their loved ones. "Even my mother, when I told her that I was going to have dialysis and everything, she began to cry… my mother's weeping as if I were dead" (P05). This participant also shared the difficult conversations she had with her child regarding a kidney transplant: "we talked a lot, me and him about this. Because he cried a lot, he wanted them to donate [a kidney] to me quickly" (P05). When asked about the impact that PD had on their families, one participant responded that her children "worry about their mom more than before. They always worry about their mom. But, they talk about things today as to where they used to didn't talk about it, you know. And now, it's like everyday stuff is brought up, you know. They might talk amongst themselves: 'What are we going to do if this happens to mom? What are we going to do if that happens to mom?' (P01). She then described the specific changes her children have made: "one of them got some surgery, it's a weight loss surgery, and she's been through a lot of exercises, working out and all of that. My son was drinking. He stopped drinking. And, I have twin girls, the other one, she had a child… and she had her child so that I would be able to see her, my grandbaby if something happened. And the other one had her surgery in case she had to give me a kidney. And my son stopped drinking for the same reason also" (P01).

The initiation of PD also impacted patient's mobility and required unanticipated adaptation to social schedules. As one participant explained, "everything changed because, well, I no longer go out as I could. There are times that we want to go camping and, well, I can't because I have to do my dialysis… there are many activities that, well, I can no longer do what I did before" (P07). Another participant shared "I have not gone out for several years. Really, I have been here, just here, in this confinement. I have not been on long trips anymore" (P08). The impact on mobility seemed to extend to participants' families as well. When asked how PD has impacted his family, a participant shared that "the changes that I have noticed in my family that, well, they no longer go out as before, right. Before they used to go out, we would go to many places, right, for a trip, on vacation. So now, now I have to haul my boxes, with my machine" (P04). While traveling was still possible, it required significant planning for transporting equipment either by car or plane. "When they leave by plane, I have to drive to carry all my things because I didn't get a chance to call Baxter to take them for me. Or sometimes there are short trips that one wants to do on the weekend… so I have to drive my car, load up the boxes and machine for my dialysis and I drive by myself right. Or we all go driving, but people get very bored when there are many hours of driving" (P04).

When asked about the most challenging aspect of doing PD, this same participant responded: "Well, the most difficult aspect for me is that when I'm out and about, I have to go do my dialysis… and socially, well, I no longer spend time with my friends the way I used to before. I would stay talking with them longer, I would go visit someone, or I would go wait for someone else. Now I have to cut my day short. At 7:00, 6:30 in the afternoon, I am already at home preparing to do dialysis" (P04). This experience was shared by another participant: "I was a person who liked to go dancing, I liked to go out to have fun, and well, not anymore, not anymore... I have to be home early to be able to connect early and be doing my dialysis" (P05). PD seemed to impact not only patient's ability to socialize and travel, but it also restricted mobility inside the home. For example, when one participant was describing how her children help her at home, she shared “they also help me in that sense, well, if I need something and I can't go out except to the kitchen, things like that. Because the tubing only reaches up to a certain… up to the bathroom” (P03). Another participant also described being confined to her bedroom while performing PD, “For my children, it was also a bit difficult because in the afternoons we mainly got together in their bedroom. Now I have to tell them ‘come to my bed, come down here’ so they can tell me what they need or how their day was and everything. But sometimes they want to do things at night and well, being on the machine I can't” (P05).

4. Family support

Family support was identified as a facilitator by all participants. Family support took many shapes and included emotional support, physical help carrying dialysis supplies, technical help troubleshooting equipment or getting the dialysis machine ready for use, and assistance with communication at health appointments and over the phone. One participant shared about the support that she received from her son, “He was in college, it was 2018, and he already knew about my illnesses. Anyway, he would come all the way from there and we would go to my appointments” (P05). She also described how her other children help her around the house, “When I started dialysis, they began to help me more. If they eat, they get up, wash their dishes, clean their rooms or sometimes, like right now when they're on vacation, they're following me and ‘what can I help you with? and how can I help you?’ I mean, well, something good came out of all this” (P05). Another participant reported that her children “help me with the things I need, to bring in the boxes for dialysis, for those kinds of things… But regularly, I am the one who takes care of everything. They only helped me in, well in... well maybe morale, right, or I don't know how to explain it... yes, yes, emotionally” (P03). One participant shared how his family helps him specifically with dialysis, “There are also times that I am late at work and my family helps me a lot to prepare the machine, open the boxes, prepare the fluid next to the machine, and well, they help me connect the first part of the machine and then I arrive and do everything else” (P04).

In some instances, family members adjusted their own schedules and responsibilities. Two partners switched to a job that had a more flexible schedule so that they could provide more support at home or be available to assist and transport participants in case of an emergency. One participant shared, “Now that that Uber company has come out, she works at Uber Eats distributing food and works the hours that she can work, and when she sees that I'm going to get home from work, she goes home and takes care of me and everything” (P04). Similarly, another participant described, “My husband, he changed to a job that was more flexible, in case I had an emergency he could come home and help me, or help me with some appointments, situation, or with anything that might happen. So, he changed jobs for a job that was more flexible in this aspect” (P02).

Individual – Need for care factors

5. Complications and symptoms related to PD

A few participants reported complications related to PD. The most reported complication was catheter site infection, but it was still uncommon. Peritonitis was reported by one participant, who had to undergo antibiotic treatment and exchange of her peritoneal catheter. Hernia was reported by two participants, but only one of them required hernia repair. Despite these complications, after appropriate treatment, participants were able to continue receiving PD at home without issues.

While complications were uncommon, symptoms that participants attributed to PD were more frequently reported. Among these, sleep disturbance, constipation, and decreased libido were the most common. One participant who struggles with insomnia shared “some days you get to sleep and sometimes you just lay there, and you are awake the whole time. Yeah, I don’t know why that is, I don't know how to combat that. You just gotta deal with that one… I used to go to sleep pretty easy. Now I struggle to sleep, and when I sleep, I wake up a lot … I have to be very tired to fall asleep right away or to not wake up frequently at night” (P06). Another participant described her struggle with sleep, “Look, in December I lasted... it wasn't December, it was in October. I lasted three months that I could not sleep. Three months when I felt that I was going to die because I couldn't sleep a single day. The doctor gave me sleeping pills and I couldn’t sleep. I felt worse and the doctor told me ‘it could be, uh, depression.’ Well, I told him, ‘is not depression, no, it is not. I don't feel bad myself” I said. But at the end, with other stronger pills that he gave me, I started to sleep and my sleep kind of became more regular” (P05). For one participant, sleep issues have lasted more than a few months: “In fact, it’s been several years that I have not been able to sleep well. In other words, I get little sleep” (P08).

All participants have either struggled with constipation and/or consistently take medications to prevent constipation. For example, one patient reported “yeah, sometimes I have constipation, a little bit. But then they gave me the oral medication and now that’s over with. I don’t have that” (P01). Another participant described, “yes, yes, that does happen to me, that's why I also take a lot, I take some medicine for overall health, right. I noticed many changes in my body since I got sick, since 6 years ago that I got sick. I did notice many changes, constipation, I do not make urine. The doctor gives me pills for constipation and it goes away" (P04).

Almost all participants endorsed changes to their sex life since starting PD. Most commonly, changes were due to decreased libido. One participant shared "I no longer have desire, to be honest. Well, the truth is, I feel like I don't have the desire to have sex" (P08). Another participant shared "before, I was very, very active [sexually] with my wife and since I got sick, well, dialysis weakens me a lot during the night and all that, and then I just feel very weak" (P04). One participant had been experiencing decreased libido chronically, which she attributed to diabetes: "I don't have a sex life. My doctor told me years ago, years ago, that women become frigid, and men become sterile when they are diabetics. I am a chronic diabetic and I have no interest whatsoever. And haven't had any in the last 7 or 8 years" (P01). There was also one participant who reported feeling self-conscious about her body due to her PD catheter, and that impacted her sex life. She explained, "sometimes it's the shame of my husband seeing the tube there, and I do feel embarrassed in front of him... And sometimes, well, with that feeling any desire goes away" (P05).

Other less common symptoms included nausea, vomiting, abdominal discomfort and/or distension. A patient who was experiencing abdominal pain with dialysis explained, "so I called the peritoneal place, and they asked me if I have been doing manual. And I said yes. And they asked me if I had been letting the air out, before putting it in. And of course, I hadn't. So, I started letting the air out before I put it in, and that pain was gone" (P01). Another participant shared, "I'm not going to lie to you, there are moments, like those of us who do dialysis know, we vomit, we have stomach pain, sometimes discomfort. I seem pregnant all the time because of the fluid that I have left during the day" (P03). There was one other participant who described abdominal cramps and distention, “the bad thing, the only thing that, well, are the cramps that I get or how my stomach fills up a lot. There are times that I can't stand it anymore... like with the fluid, the fluid gets inside, well, I stay as if I were pregnant and, uh, a lot of discomfort” (P07).

6. Improved health with PD

However, improvement of symptoms related to renal failure seemed to overshadow any negative experiences related to complications, symptom burden, and the psychosocial impact of starting dialysis. Participants reported improvement in leg swelling, weight gain from volume overload, and fatigue after dialysis initiation. The change that was most mentioned by participants was an improvement in energy levels, which allowed participants to meaningfully spend time with loved ones, and work during the day while performing dialysis at night. One participant shared that she had not been able to spend time with her dog and grandchildren in a long time due to her illness but that changed after she started PD. She recounted, “and then one day, I was just like ‘come on, let's go outside’ with the grand baby and I said ‘look, you grab your bike and I'll take the dog.’ And I walked like a block and a half, and it was absolutely wonderful. I mean it does make you feel better after like a solid week of using it. You do get energy back and it just makes you feel better” (P01). Participants often compared their lives before and after dialysis. For example, one individual reported, “Before dialysis, I felt that my legs were very swollen, my legs were stained from the knee down, with many red spots. I did work, but I kind of felt exhausted all day, I kind of got up and was sleepy all day... I feel much better than before the dialysis. Because right now dialysis does the work for the kidneys” (P03). After starting dialysis, this participant was able to go back to a full-time job. She proudly shared how she was able to get health insurance and is now “fighting for a transplant” (P03). Another participant described “before, I used to feel tired, I felt irritable… I wanted to be lying down, and

I wanted to lie down, and I felt very tired. After the dialysis, I have felt more energetic, I feel better" (P05).

Health system factors

7. Support from dialysis team

All participants reported that their dialysis team, and in particular their dialysis nurses, have been instrumental in answering questions, addressing concerns, and/or facilitating communication with their nephrologists. One participant expressed, "I don't know if I got very lucky with my nurse who is very specialized in all this, and she sometimes gets me out of trouble" (P04). This sentiment was shared by other participants. Dialysis nurses helped troubleshoot technical issues, provided education, answered questions, and appropriately triaged serious complications, like peritonitis. Among Spanish-speaking participants, only two reported ever having a dialysis nurse who also spoke Spanish, and none reported ever having a bilingual nephrologist. Participants did not think that this negatively impacted the quality of the care they received. However, there was a consensus that the quality of the communication would be better with a Spanish-speaking health care provider.

8. Underutilization of professional health interpreters

In addition to a lack of bilingual dialysis providers, Spanish-speaking participants also described underutilization of professional health interpreters. Participants commonly got by with limited English skills and had their own criteria for requesting an interpreter, based on the perceived complexity of the conversation. For example, one participant shared "when I see that it is something difficult, I better tell him [the doctor] to put the interpreter on" (P03). Other times, participants relied on their nurses or nephrologists to determine whether an interpreter was needed: “When it's a routine visit, the doctor tells me ‘No, you can do it yourself’ and if I do, I speak a little English and if she understands me, I understand her, and she says ‘ok,’ we're fine” (P04). Other times, “the doctor herself tells me ‘now we are going to have an interpreter because this is very important for you’” (P04). Other participants reported consistently using either a professional or an *ad hoc* interpreter, based on their physician’s preference: “My doctor, my nephrologist, well, he speaks English, but I always have an interpreter or someone to help me. Because he always looks for someone to help me, to understand everything he tells me” (P05).

Lack of professional healthcare interpreters was described by one participant: “There, in Seattle, they give me an interpreter. But as soon as I go to the [clinic] in Mountlake Terrace, they don't give me an interpreter because they don't have one” (P07). When interpreters were available, participants’ attitudes towards the quality and accuracy of the interpreted conversation influenced utilization of professional interpreters. For example, one participant noted, “I have noticed that sometimes the interpreters don't tell you things as they are, or they take a long time to [interpret my] answer and I get inpatient… and even the doctor turns and looks at me because sometimes I nod yes or no, it depends on the question, and he [the doctor] already has the answer and they are just going to tell the doctor what I said” (P05). This participant preferred to use an *ad hoc* interpreter, her son.

When asked if there are any resources or information that would make receiving PD easier, a Spanish-speaking participant offered, “[I wish] that they had people who spoke Spanish or people who could explain in one's language, to be able to understand or to be able to communicate more freely or comfortably… Because sometimes you do have questions, but since you can't explain the question well, you don't ask it” (P02). Another Spanish-speaking participant shared, “I would like if they could have all the materials in Spanish, because they gave me the books, but the books are in English. Yes, really, I'm not really going to lie to you, I didn't read them. They have given me instructions for various things in English and I say ‘how do I do it?’” (P05).

Societal factors

9. Impact of immigration policy

Immigration policy negatively impacted care for one participant. A participant got an abdominal hernia from his peritoneal catheter placement because he was not allowed to recover appropriately after surgery: “They explained to me that I couldn't lift many things, right. But since I work in construction and since I don't have any, I'm not legal in the country, I couldn't receive help from the government, I couldn't receive financial help from the government. So I had to work to cover my expenses, food, rent, shoes, you know, and my family. So they operated on me and three days later I was already there, working and lifting things. And I tried not to lift the heaviest stuff. My employer knew, but I had to do it” (P04). Abdominal hernias have been identified as a risk factor for retroperitoneal leak, a cause for acute ultrafiltration failure.[18] However, this patient did not experience issues with ultrafiltration. He underwent hernia repair and was able to continue PD with no issues, consistent with research showing that most patients who undergo hernia repair can continue with PD.[19]

Preference for PD

Despite some of the barriers described above, all participants reported that they would still choose PD over other dialysis modalities if given the choice. Several reasons emerged for their preference for PD, including the ability to perform PD overnight and work during the day, the comfort of doing PD from home and not having to travel to the dialysis center a few times a week, the ease of doing PD, and the ability to be with family while performing PD. One participant also highlighted that while traveling with the PD machine can be cumbersome, her ability to travel would be even more restricted if she was on HD and had to go to a dialysis center several times per week.

Discussion

To our knowledge, this is the first study to explore barriers to PD retention among Black and Latino patients from the patient perspective. This study adds to the existing literature on barriers to initiating and staying on PD, centering the experiences of Black and Latino patients, a population that is disproportionately impacted by kidney failure[3] and encounters disparities in the utilization of home dialysis.[4,5] In this qualitative analysis, positive attitudes towards dialysis, self-efficacy to perform PD, family support, improvements in health after PD, and support from the dialysis team emerged as facilitators to PD retention while a challenging transition to PD, impact on mobility and social life, complications and symptoms related to PD and underutilization of professional health care interpreters acted as barriers. Identification of barriers to staying on PD through our current work will inform future interventions to support Black and Latino patients with kidney failure and directly address the equity gap in home dialysis.

Prior retrospective studies have described multiple reasons why patients may stop PD. In a study conducted in China, peritonitis was identified as the most common medical reason for stopping PD, while lack of caregivers and losing confidence in the ability to perform home dialysis was cited as the most common non-medical reason.[20] A single center retrospective study conducted in the United States found that psychosocial factors were the most common reason for controllable withdrawal from PD regardless of time on therapy.[21] These psychosocial factors included burden of performing PD, declining mental health, and collapse of support network.[21] In our study, only one participant had developed peritonitis, which required catheter exchange. However, she was able to continue PD after appropriate treatment. All participants in our study had a strong support system and were confident in their ability to perform dialysis at home. Limited or lack of home space was not described by participants in our study. Our future qualitative research will explore if the factors described in the above retrospective studies resonate with Black and Latino patients who have converted from PD to in-center HD.

In our study, sleep disturbance was a commonly reported symptom that participants temporarily correlated to PD initiation. Our findings were corroborated by previous studies that showed patients who undergo PD have sleep disorders and poor sleep quality.[22-24] Interestingly, undergoing overnight exchanges does not seem to influence sleep quality as patients who undergo automated PD have been shown to have similar sleep quality indices as patients who undergo HD during the day.[22] This suggests that factors other than PD itself may contribute to poor sleep quality. Depression has been hypothesized to be one of those factors as it commonly affects patients on chronic dialysis and many patients who have depression also have poor sleep quality.[22,23] In a large cross-sectional study of patients who were new to either PD or HD, close to 50% of patients reported symptoms of insomnia and 28% of patients had symptoms of depression.[23] Given the high prevalence of depression among patients who undergo long-term dialysis, dialysis care should include depression screening and the provision of psychosocial interventions that have been shown to reduce depressive symptoms in this patient population, including cognitive behavioral therapy and exercise or relaxation techniques.[25]

While we did not screen for symptoms of depression in our study, several participants reported psychological distress at the time of dialysis initiation. Research has mostly focused on the treatment of depression among patients on long-term dialysis and less is known about management of mild or moderate distress, which is also common in this patient population.[26,27] Additionally, barriers to proactively identifying and managing patient distress exist. Qualitative and mixed methods studies have described that, although renal unit staff recognized the value of supporting distressed patients, they lacked the skills, confidence, and training to identify and respond to patient distress.[26,28] In addition to providing staff with training, regular depression and distress screening and the integration of mental health services into kidney care can facilitate diagnosis and treatment before and after dialysis initiation. Support groups have been shown to improve quality of life, depressive symptoms, and coping skills in patients with cancer[29] and might be beneficial for patients who are undergoing dialysis and their caregivers, potentially improving PD retention.[30]

Consistent with previous research, our study identified the underutilization of professional health interpreters as a potential area for quality improvement.[31] At the systems level, provision of professional interpreting services and guidelines for their use are essential to ensure that Spanish-speaking patients with kidney failure receive language-concordant and patient-centered care. While participants in our study received PD training in their preferred language or with assistance from an interpreter, subsequent encounters with members of their dialysis team were often characterized by inconsistent interpreter use. Additionally, educational materials were not always provided in the patient’s preferred language. One qualitative study among Latino patients who received emergency-only HD found that Latino patients with limited English proficiency did not receive language concordant or culturally sensitive dialysis education.[32] In that study by Novick et al., participants identified multiple elements that they wished were incorporated into their dialysis education, including the use of culturally concordant care, use of visual aids, and description of expected symptoms and the impact that dialysis would have in their everyday lives.[24] Incorporation of these elements during dialysis education and after dialysis initiation may improve self-efficacy and alleviate distress. It is important to highlight that Spanish is the second most common language spoken in the United States, surpassed only by English.[33] For patients who prefer to communicate in less commonly spoken languages, interpreter services use may be even more inconsistent.

Our study has some limitations, including limited generalizability, potential recall bias, and a small sample size. Additionally, our findings mostly reflect the experiences of Latino patients as we only included two Black participants. The patients who participated in this study were recruited from a single community dialysis provider, and our results may not be generalizable to patients receiving dialysis care in other settings. Participants also had variable times on PD, ranging from 8 months to 72 months. It is possible that participants who have performed PD for a while have had time to adapt and may not recall the multiple factors that made dialysis challenging at the beginning. While the total number of participants is low, the depth of information they shared with us is a strength of this study. Additionally, recruitment is ongoing, with an anticipated 15-20 interviews needed in total to achieve thematic saturation. We will also be conducting 15-20 interviews among Black and Latino patients who have stopped PD and converted to in-center HD to gain a more nuanced understanding of the factors that may lead to lower rates of PD retention among minoritized patients with kidney failure. Our goal is to have a balanced distribution of Black and Latino patients in both groups.

This qualitative study identified several barriers and facilitators to PD retention from the perspectives of Black and Latino patients with kidney failure who are currently receiving PD. Positive attitudes towards dialysis, self-efficacy, family support, improvements in health after PD, and support from the dialysis team emerged as facilitators to PD retention. A challenging transition to PD, impact on mobility and social life, complications and symptoms related to PD, and underutilization of professional health interpreters emerged as barriers. Interventions that integrate mental health services into dialysis care, regular depression screening, staff training to identify and respond to patient distress, support groups, and strict guidelines for the usage of professional health interpreters may help close the equity gap in home dialysis for Black and Latino patients.

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Supplemental Table 1. Interview questions based on Andersen's behavioral model of health service use[2]

Domain	Sample questions
Societal	Has anyone in the dialysis team, including nurses and physicians, ever made comments or acted in a way that made you think or feel that you could not do PD at home based on your race, gender, age or ability to speak English?
Health services system	What technical support or services do you wish you had that would make it easier to continue PD at home?
Individual – Predisposing	How do you think that the information and the training you received prepared you for performing PD at home?
Individual – Enabling	If your family member, caregiver, or person who normally helps you is unavailable, what happens then?
Individual – Need for care	How has your health changed since starting PD?

Supplemental Table 2. Translated quotes

Original quote in Spanish	English translation
“gracias a Dios y gracias a esta máquina yo estoy viva.” – P03	Thanks to God and thanks to this machine I am alive
“Mi maquina es la mejor amiga que tengo del mundo ahorita.” – P03	My machine is the best friend I have in the world right now
“Entonces cuando me dijeron de la peritoneal, que iba a ser en mi casa, que me iban a preparar, que me iban a dar una clase y todo, pues yo sin pensarla yo dije ‘yo quiero la peritoneal.’” – P07	Then, when they told me about peritoneal [dialysis], that it would be at home, that they would train me, that they would provide a class and everything, without thinking twice I said ‘I want the peritoneal one’
“me dicen que yo puedo hacer mi vida normal, que yo puedo comer todo lo que yo quiera y que con moderación verdad. Entonces yo dije ‘yo quiero la peritoneal, yo quiero que me hagan la peritoneal.’” – P04	They tell me that I can live a normal life, that I can eat anything I want, with moderation, right. Then I said ‘I want the peritoneal one, I want to undergo the peritoneal one’
“Al principio lo miré como imposible, prácticamente indecisa de sí yo iba a aprender eso bien. Pero después cuando terminó el proceso y todo me sentí con un poco de miedo todavía, pero, dentro de mí, sentía que si podía hacerlo.” – P02	At first, I looked at it as impossible, I was practically unsure if I was going to learn it well. But later, when the process was finished and everything, I still felt a little afraid, but deep inside, I felt that I could do it
Primero se veía difícil, pero ya cuando si aprendes todo dices “no, está bien, no pasa nada.” La verdad, no, no, no se me ha hecho complicado. – P03	It seemed difficult at first, but when you learn everything you say ‘no, it's okay, it’s nothing.’ The truth is, no, no, it hasn't been complicated for me
“fue algo completamente nuevo. Fue algo que nunca había pensado en si algún día iba a pasar o este si algún día lo iba a necesitar. Fue prácticamente como un balde de agua el que me cayó, un balde de agua fría, a mí y a mi familia” – P02	“It was something completely new. It was something that I had never thought about if one day it was going to happen or if someday I was going to need it. It was practically like a bucket of water that fell on me, a bucket of cold water, on me and my family."
Cuando me dijeron, “vas a hacer diálisis” y tú sabes todos los malos comentarios de la gente. Para mí era como “no quiero hacerlo, no quiero estar ahí, no quiero que me hagan eso.” Lloré mucho cuando mi primer día que ya tenía yo mi tubo y me llevaron a, pues a las clases y a ver cómo me iba a empezar a hacer las diálisis, también lloré – P05	When they told me, ‘you're going to do dialysis’, and you know all the bad comments people make. For me, it was like "I don't want to do it, I don't want to be there, I don't want to have that done to me." I cried a lot the first day that I already had my tube and they took me to, well, to classes and to see how I was going to start dialysis, I also cried.
“fue muy duro no te voy a mentir o sea desde que te dijeron “ya te vas a dializar.” Yo siempre fui una persona muy movida, entonces que me digan “vas a hacer esto,” digo “wow.”	It was very hard, I'm not going to lie to you, that is, since they told you “you're going to go on dialysis.” I have always been a very active person, so when they told me “you are going

Sentía un cuadro muy difícil. Pero después dije, "ok no puedo llorar." O sea, o sea sí lloré, claro pero no me la puedo pasar llorando, no me la puedo pasar quejando" – P03	to do this," I say "wow." I felt a very difficult outlook. But then I said, "ok I can't cry." I mean, I did cry, of course, but I can't spend life crying, I can't spend life complaining.
"Yo me ponía muy triste cuando iba a hacerme la hemodiálisis del pecho en el centro de diálisis. A mí me deprime mucho y yo sentía que, yo todos los días lloraba ahí en el centro de diálisis. Y yo me dije, "esto no va a ser, esto, esto no lo va a aguantar yo," porque yo veía mucha gente enferma. Y yo decía, "ese es mi destino." Y me bajaba la moral, me bajaba mi autoestima, me bajaba baja todo. Y yo decía "no, yo no quiero estar así." – P04	I used to get very sad when I went to do chest HD at the dialysis center. It depresses me a lot and I felt that, every day I cried there in the dialysis center. And I said to myself, 'this is not going to work, this, I am not going to put up with this,' because I saw many sick people. And I said, 'That is my destiny.' And my morale dropped, my self-esteem dropped, everything dropped. And I said 'no, I don't want to be like this.'
"Hasta mi mamá, cuando le dije que me iban a hacer diálisis y todo, empezó a llorar… un llanto de mi mamá como que si yo estuviera muerta." – P05	Even my mother, when I told her that I was going to have dialysis and everything, she began to cry… my mother's weeping as if I were dead.
"Platicamos mucho yo y él de esto. Porque él lloraba mucho, él quería que rápido me donaran." – P05	We talked a lot, me and him about this. Because he cried a lot, he wanted them to donate [a kidney] to me quickly.
"todo cambió porque pues ya no no salgo como podía salir. Hay veces que tenemos ganas de ir a acampar y pues no puedo por lo mismo que me tengo que hacer mis diálisis… hay muchas actividades que pues ya no puedo hacer lo que hacía antes." – P07	Everything changed because, well, I no longer go out as I could. There are times that we want to go camping and, well, I can't because I have to do my dialysis… there are many activities that, well, I can no longer do what I did before.
"yo ya tengo varios años que no salgo fuera. Ya verdad, yo he estado aquí, nomás aquí, lo que es el encierro. No he salido más así a viajes largos. – P08	I have not gone out for several years. Really, I have been here, just here, in this confinement. I have not been on long trips anymore.
"Los cambios que he notado yo en mi familia que que pues que ya no salen como antes verdad. Antes salían, salíamos a muchos lados verdad, a pasear, de vacaciones. Entonces pues ahora, ahora pues tengo que acarrear con mis cajas, con mi máquina." – P04	Well, the changes that I have noticed in my family that, well, they no longer go out as before, right. Before they used to go out, we would go to many places, right, for a trip, on vacation. So now, now I have to haul my boxes, with my machine.
"cuando ellos se van en avión yo tengo que irme manejando por acarrear todas mis cosas y por qué no alcancé a hablarle a Baxter para que me las llevara. O a veces son viajes este rápidos que uno quiere hacer el fin de semana… Entonces este tengo que agarrar mi carro, subir cajas y máquinas para mi diálisis y yo irme manejando verdad. O nos vamos todos	when they leave by plane, I have to drive to carry all my things because I didn't get a chance to call Baxter to take them for me. Or sometimes there are short trips that one wants to do on the weekend… so I have to drive my car, load up the boxes and machine for my dialysis and I drive by myself right. Or we all

manejando, pero sí, la gente se aburre mucho cuando son muchas horas de manejo." – P04	go driving, but people get very bored when there are many hours of driving.
"pues el aspecto más difícil para mí es que cuando cuando estoy en la calle tengo que irme a hacer mi diálisis… y socialmente, pues ya no convivo con mis amigos como antes. Pues me quedaba platicando con ellos más tiempo, iba a visitar a alguien, o iba a esperar a otra persona. Ahora ya tengo que yo recortar mi día. A las 7:00, 6:30 de la tarde ya estar en mi casa preparándome para hacer la diálisis." – P04	Well, the most difficult aspect for me is that when I'm out and about, I have to go do my dialysis… and socially, well, I no longer spend time with my friends the way I used to before. I would stay talking with them longer, I would go visit someone, or I would go wait for someone else. Now I have to cut my day short. At 7:00, 6:30 in the afternoon, I am already at home preparing to do dialysis.
"yo era una persona que me gustaba ir a bailar, me gustaba salir pues a divertirme, y pues ahora ya no, ya no… tengo que estar en casa este temprano para poderme conectar temprano y estar este haciéndome mis diálisis. – P05	I was a person who liked to go dancing, I liked to go out to have fun, and well, not anymore, not anymore... I have to be home early to be able to connect early and be doing my dialysis.
"Me ayudan en qué sentido también, pues que si necesito algo y yo ya no puedo salir que a la cocina, cosas así. Porque el cable llega a una cierta… hasta el baño." – P03	They also help me in that sense, well, if I need something and I can't go out except to the kitchen, things like that. Because the tubing only reaches up to a certain… up to the bathroom.
"Para mis hijos pues también fue algo un poco difícil porque por las tardes principalmente nos nos nos juntábamos en su recamara. Ahora tengo que decirles "vengan a mi cama, vengan acá abajo" para que me digan que que necesitan o cómo les fue el día y todo. Pero a veces quieren hacer ellos cosas de noche y pues estando en la máquina no puedo." – P05	For my children, it was also a bit difficult because in the afternoons we mainly got together in their bedroom. Now I have to tell them "come to my bed, come down here" so they can tell me what they need or how their day was and everything. But sometimes they want to do things at night and well, being on the machine I can't"
"Él estaba en la universidad, fue del 2018, y ya sabía de mis enfermedades. De todos modos venía desde allá y nos íbamos a mis citas." – P05	He was in college, it was 2018, and he already knew about my illnesses. Anyway, he would come all the way from there and we would go to my appointments.
"ellos cuando empecé con las diálisis empezaron a como dices tú, me ayudan más. Que si comen, se levantan, lavan sus trastes, limpian sus cuartos o a veces, como ahorita que están de vacaciones, este andan detrás de mí y "¿a qué te ayudo? y ¿a qué te ayudo?" Digo, bueno pues algo salió bueno de todo esto. – P05	When I started dialysis, they began to help me more. If they eat, they get up, wash their dishes, clean their rooms or sometimes, like right now when they're on vacation, they're following me and 'what can I help you with? and how can I help you?' I mean, well, something good came out of all this.
Me ayudan como en las cosas que necesito, de meter las cajas para para la diálisis, para para todo ese tipo de cosas… Pero regularmente yo soy la que me encargo de todo. Ellos	They help me with the things I need, to bring in the boxes for dialysis, for those kinds of things… But regularly, I am the one who takes care of everything. They only helped me

solamente me ayudaron en en, pues en… pues a lo mejor moralmente, verdad, o no sé cómo explicarlo… sí, sí, emocionalmente – P03	in, well in... well maybe morale, right, or I don't know how to explain it... yes, yes, emotionally
“también hay veces que a mí se me hace tarde en el trabajo y mi familia me ayuda mucho a preparar la máquina, abrir las cajas, a preparar las aguas ahí junto a la máquina, y pues me ayudan a conectar la primera parte de la máquina y ya después yo llego y hago todo lo demás.” – P04	“There are also times that I am late at work and my family helps me a lot to prepare the machine, open the boxes, prepare the fluid next to the machine, and well, they help me connect the first part of the machine and then I arrive and do everything else.”
“ahora que salió esa compañía del uber, ella ella trabaja en el uber eats repartiendo comida y trabaja las horas que que que puede trabajar y cuando ya ve ella que voy a llegar de trabajar se va a la casa y me atiende y todo” – P04	Now that that uber company has come out, she works at uber eats distributing food and works the hours that she can work, and when she sees that I'm going to get home from work, she goes home and takes care of me and everything
“mi esposo, él cambio a un trabajo que fuera más flexible, por si yo tuviera alguna emergencia, él poder venir a la casa y auxiliarme, o ayudarme en algunas citas, situación, o en alguan cosa que pudiera pasar. Entonces el cambió de trabajo para un trabajo que fuera más flexible en este aspect” – P02	“My husband, he changed to a job that was more flexible, in case I had an emergency, he could come home and help me, or help me with some appointments, situation, or with anything that might happen. So he changed jobs for a job that was more flexible in this aspect."
“Mira, en diciembre duré… no fue diciembre, fue en octubre. Duré tres meses que no pude dormir. Tres meses yo sentía que ya me iba a morir porque yo no podía dormir ni un día. Este el doctor me dio pastillas para dormir y no dormía. Más mal me sentía y me dijo el doctor “puede ser, este, depresión.” Pues le dije, “depresión no es, no, no es. No me siento mal yo” dije, pero este al último con otras pastillas más fuertes que me dio este empecé a dormir y ya como que ya se me reguló el sueño.” – P05	Look, in December I lasted... it wasn't December, it was in October. I lasted three months that I could not sleep. Three months when I felt that I was going to die because I couldn't sleep a single day. The doctor gave me sleeping pills and I couldn’t sleep. I felt worse and the doctor told me ‘it could be, uh, depression.’ Well, I told him, ‘is not depression, no, it is not. I don't feel bad myself” I said. But at the end, with other stronger pills that he gave me, I started to sleep and my sleep kind of became more regular.
“de hecho sí ya tengo ya varios años que no he podido conciliar mi sueño bien. O sea, es poco lo que duermo.” – P08	“In fact, it’s been several years that I have not been able to sleep well. In other words, I get little sleep.”
“Sí, eso sí, eso sí me pasa a mí por eso este también yo tomo mucha, tomo alguna medicina para para la constitución verdad. Noté muchos cambios en mi organismo de ahora que me enfermé de 6 años para acá que me enfermé. Si noté muchos cambios, que estreñimiento, este no no orino. El doctor me	Yes, yes, that does happen to me, that's why I also take a lot, I take some medicine for overall health, right. I noticed many changes in my body since I got sick, since 6 years ago that I got sick. I did notice many changes, constipation, I do not make urine. The doctor

da me da pastillas para la constipación y se me quita" – P04	gives me pills for constipation and it goes away.
"me siento como que ya no me dan ganas la verdad. Pues la verdad me siento sin ganas de tener sexo" – P08	I no longer have desire, to be honest. Well, the truth is, I feel like I don't have the desire to have sex.
"antes yo era muy muy activo con mi esposa y desde que me enfermé para acá, pues es que la diálisis debilita mucho en el transcurso de la noche y todo eso y luego este, este queda uno muy débil" – P04	Before, I was very, very active [sexually] with my wife and since I got sick, well, dialysis weakens me a lot during the night and all that, and then I just feel very weak
"a veces es la pena de que mi esposo me vea el tubo ahí y si me da me da pena con él… Y a veces pues como con el sentido pues ya se te quitan las ganas" – P05	sometimes it's the shame of my husband seeing the tube there, and I do feel embarrassed in front of him... And sometimes, well, with that feeling any desire goes away.
"No te voy a mentir, hay momentos, como los que nos hacemos las diálisis sabemos, tenemos vómito, tenemos dolor de estómago, a veces incomodidad. Yo todo el tiempo me veo como embarazada por el agua que me queda en el día" – P03	I'm not going to lie to you, there are moments, like those of us who do dialysis know, we vomit, we have stomach pain, sometimes discomfort. I seem pregnant all the time because of the fluid that I have left during the day.
"Pues lo malo, lo único que, pues sí, son los calambres que me dan o como me lleno mucho del estómago. Hay veces que sí ya no la aguanto… como con el agua, que se me entra el agua, pues sí quedo como si estuviera embarazada y, este, mucha incomodidad." – P07	The bad thing, the only thing that, well, are the cramps that I get or how my stomach fills up a lot. There are times that I can't stand it anymore... like with the fluid, the fluid gets inside, well, I stay as if I were pregnant and, uh, a lot of discomfort.
"antes de la diálisis yo sentía que se me hinchaban mucho mis piernas, me manchaba de las piernas en lo que era todo de la rodilla para abajo, muchas con manchas rojas. "trabajaba sí, pero como que me sentía como agotada todo el día, como que me levantaba y como que tenía sueño todo el día… Me siento mucho mejor que antes de la diálisis. Porque ya ahorita la diálisis le hace el trabajo a los riñones" – P03	Before dialysis, I felt that my legs were very swollen, my legs were stained from the knee down, with many red spots. I did work, but I kind of felt exhausted all day, I kind of got up and was sleepy all day... I feel much better than before the dialysis. Because right now dialysis does the work for the kidneys
"yo regresé a mi trabajo, agarré mi aseguranza y estoy peleando por luchar por un trasplante. – P03	I went back to work, got my insurance and I'm fighting, to fight for a transplant.
antes me sentía cansada, me sentía irritable… todo el día estaba, quería estar acostada y quería estar acostada y me sentía muy cansada. Después de las diálisis, me he sentido con más energía, me siento mejor. – P05	Before, I used to feel tired, I felt irritable… I wanted to be lying down and I wanted to lie down, and I felt very tired. After the dialysis I have felt more energetic, I feel better.

“no sé si me tocaría mucha suerte con mi enfermera que es muy especializada en todo esto y ella a veces me saca de de apuros” – P04	I don't know if I got very lucky with my nurse who is very specialized in all this, and she sometimes gets me out of trouble
Cuando yo veo que es algo difícil mejor le digo [al doctor] que me ponga al intérprete – P03	When I see that it is something difficult, I better tell him [the doctor] to put the interpreter on
Cuando es visita regular la doctora me dice “No, tú sólo puedes” y sí yo le hago, yo hablo un poco inglés y si me me entiende, yo la entiendo y ya me dice “ok,” quedamos bien… la doctora misma me dice “ahora sí vamos a poner intérprete porque esto es muy importante para ti.” – P04	When it's a routine visit, the doctor tells me ‘No, you can do it yourself’ and if I do, I speak a little English and if she understands me, I understand her, and she says ‘ok,’ we're fine... the doctor herself tells me ‘now we are going to have an interpreter because this is very important for you.’
“mi doctor, mi nefrólogo, pues habla inglés pero siempre tengo intérprete o tengo una persona que me ayude. Porque él siempre busca a alguien quien me ayude a, a entender todo lo que me dice” – P05	My doctor, my nephrologist, well, he speaks English, but I always have an interpreter or someone to help me. Because he always looks for someone to help me, to understand everything he tells me
“allá en Seattle me ponen intérprete. Pero apenas me voy a la de Mountlake Terrace no me ponen intérprete porque no tienen.” P07	There, in Seattle, they give me an interpreter. But as soon as I go to the [clinic] in Mountlake Terrace, they don't give me an interpreter because they don't have one.
“yo me he fijado que los intérpretes no te dicen a veces las cosas como son, o se tardan bien mucho para contestar y yo me desespero… y hasta el doctor voltea y me ve porque yo a veces le contesto con la cabeza que sí o que no, depende de la pregunta, y él ya tiene la respuesta y ellos apenas van a decirle al doctor lo que yo dije.” – P05	I have noticed that sometimes the interpreters don't tell you things as they are, or they take a long time to [interpret my] answer and I get inpatient… and even the doctor turns and looks at me because sometimes I nod yes or no, it depends on the question, and he [the doctor] already has the answer and they are just going to tell the doctor what I said.
“a mí me explicaron que no podía cargar muchas cosas, verdad. Pero como yo trabajo en la construcción y como como no tengo yo, no estoy legal en el país, no podía recibir ayuda del gobierno, no podía recibir ayuda económica del gobierno. Entonces yo tenía que trabajar para solventar mis gastos, de comida, renta, zapatos, entiende, y lo de mi familia. Entonces me operaron y yo a los 3 días ya estaba ahí trabajando y levantando cosas. Y yo trataba de no levantar lo más pesado. Mi patrón sabía, pero yo tenía que hacerlo.” – P04	They explained to me that I couldn't lift many things, right. But since I work in construction and since I don't have any, I'm not legal in the country, I couldn't receive help from the government, I couldn't receive financial help from the government. So I had to work to cover my expenses, food, rent, shoes, you know, and my family. So they operated on me and three days later I was already there, working and lifting things. And I tried not to lift the heaviest stuff. My employer knew, but I had to do it.
“mi hijo le preguntó por un riñón y el doctor dijo “pues no se puede, porque ella no es ciudadana.” Entonces ahí si me sentí como	my son asked about a kidney and the doctor said ‘well, that can’t happen, because she's not a citizen.’ So then I felt discriminated

como discriminada. Como diciendo “ok, pero soy un ser humano” pensé yo verdad. Pero después ya lo pensé después este, le dije a mi hijo “pues en realidad hijo, pues tienen razón, estoy en un lugar donde no es donde yo nací, donde yo crecí,” le digo. Y también el cómo él es nacido aquí, el sí decía “pero yo soy nacido aquí mamá y yo…” “pues sí mijo” le digo, “pero no es la misma.” – P05	against. ‘Okay, but I'm a human being’, I thought, right. But then I thought about it, then I told my son ‘well, actually son, they are right. I am in a place that is not where I was born, where I grew up,’ I tell him. And also, because he was born here, he did say ‘but I was born here mom and I…’ ‘Well, yes son,’ I tell him, ‘but it's not the same’
“que tuvieran personas que hablaran español o personas que que pudieran explicar en el idioma de uno, para poder entender o como poder decir uno un poco más libre y cómodo… Porque a veces uno si tiene preguntas, pero como no puede explicar la pregunta bien, no la dice” – P02	“[I wish] that they had people who spoke Spanish or people who could explain in one's language, to be able to understand or to be able to communicate more freely or comfortably… Because sometimes you do have questions, but since you can't explain the question well, you don't ask it”
“me gustaría que pudieran este tener todas las cosas en en español, porque me dieron los libros, pero los libros están en inglés. Sí este pues en realidad no te voy a mentir, no los leí. Me han dado pues como instrucciones de varias cosas que en inglés y digo “¿yo cómo le hago?” – P05	I would like if they could have all the materials in Spanish, because they gave me the books, but the books are in English. Yes, really, I'm not really going to lie to you, I didn't read them. They have given me instructions for various things in English and I say ‘how do I do it?’
“yo pienso que ahí sería bueno una, un no sé si un psicólogo o una terapeuta, que te esté llevando tu transición de estar sin nada a hacer una diálisis. Porque sí pienso que mucha gente se derrota en este tiempo, cuando dices ya te van a hacer diálisis y piensas que ya no vas a servir para nada… Pero cuando ya te empiezas a hacer las diálisis, ves tú tu cambio que en vez de sentirte cansada te sientes mejor. Entonces ya, como que ya no ocupas a la persona que te esté ayudando psicológicamente, porque ya tú ves que lo que te están haciendo te está ayudando en vez de perjudicar” – P05	“I think that it would be good to have, I don't know if a psychologist or a therapist, who is taking you through your transition from being without anything to doing dialysis. Because I do think that many people are defeated at this time, when you say they are going to give you dialysis and you think that you will no longer be good for anything... But when you start to do dialysis, you see your change that instead of feeling tired you feel better. So now, it's like you no longer need the person who is helping you psychologically, because you already see that what they are doing to you is helping you instead of harming you."