


The Experience of Primary Caregivers of Undocumented Immigrants with End-Stage Kidney Disease that Rely on Emergency-Only Hemodialysis



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BACKGROUND: Undocumented immigrants with end-stage kidney disease (ESKD) who rely on emergency-only hemodialysis (dialysis only after an emergency department evaluation) face psychosocial distress. Emergency-only hemodialysis (EOHD) is likely burdensome for primary caregivers as well.

OBJECTIVE: To understand the experience of primary caregivers of undocumented immigrants with ESKD who rely on emergency-only hemodialysis.

DESIGN, SETTING, AND PARTICIPANTS: A qualitative, semi-structured interview study to assess the experiences of primary caregivers of undocumented immigrants with ESKD at a safety-net hospital in Denver, Colorado from June 28 to November 15, 2018. Applied thematic analysis was used to analyze interviews.

MAIN OUTCOMES AND MEASURES: Themes and subthemes.

RESULTS: Twenty primary caregiver participants had a mean (SD) age of 46 (17), 13 (65%) were female, 7 (35%) were in an adult child caregiver role, and 13 (65%) were spouses. Five themes and 17 subthemes (in parentheses) were identified: (1) Caregiver role (providing emotional, physical, and economic support, advocacy and care navigation), (2) Caregiver burden (anxiety related to patient and personal death, emotional exhaustion and personal illness, struggle with finances, self-care and redefining relationship), (3) Unpredictable EOHD (acute episodes of illness that trigger emergency, stress when patient is denied dialysis, impact on work and sleep, and emotional relief after a session of EOHD), (4) Effect on children (dropping out or missing school, psychosocial distress, children assuming caregiver responsibilities, and juggling multi-generational caregiving of children), (5) Faith and appreciation (comfort in God and appreciation of healthcare).

CONCLUSIONS AND RELEVANCE: Caregivers of undocumented immigrants with ESKD who rely upon EOHD experience caregiver burden and distress. The impact of EOHD on caregivers should be considered when

assessing the consequences of excluding undocumented immigrants from public insurance programs.

KEY WORDS: health services research; immigrants; undocumented; health disparities; hemodialysis.

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INTRODUCTION

Undocumented immigrants in the USA are ineligible for Medicare or full Medicaid benefits. In most US states, their care falls to safety-net hospitals and free clinics. For hospitals to receive Medicaid reimbursement for care, the Emergency Medical Treatment and Active Labor Act (EMTALA) states that care must be for “the treatment of an emergency medical condition.^{1, 2}” This is particularly problematic for the estimated 6500 undocumented immigrants with end-stage kidney disease (ESKD) who may not be eligible for standard care (i.e., three times per week hemodialysis or home peritoneal dialysis).¹ Instead, these primarily young and Latino undocumented immigrants with ESKD must wait until they are at the brink of death to receive emergency-only hemodialysis (EOHD).³ To receive EOHD, patients are evaluated in an emergency department (ED) and must be critically ill, which is variably defined but generally includes symptoms or objective findings associated with hyperkalemia, uremia, or fluid overload.^{1, 4} Additionally, patients suffer tremendous physical and psychosocial distress from the weekly symptom accumulation, near-death experiences, and from witnessing the effect of EOHD on their own family caregivers, who witness the accumulating symptoms that trigger critical illness.⁵

Little is published, however, about how EOHD affects the family caregivers as a relevant factor potentially affecting access to standard dialysis for undocumented immigrants. This study uses a qualitative research design to describe the

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Table 1 Characteristics of Caregivers for Adults Receiving Emergency-Only Hemodialysis

Characteristic	All participants (N = 20)
Age, years	
Mean (SD)	46.1 (16.8)
Median (IQR)	50.5 (32.3–58.8)
Sex	
Male	7 (35%)
Female	13 (65%)
Primary language	
English	0 (0%)
Spanish	20 (100%)
Marital status	
Married	15 (75%)
Single	4 (20%)
Widowed	1 (5%)
Caregiver role	
Adult child	7 (35%)
Spouse	13 (65%)
Other	0 (0%)
Household income	
< \$15,000	17 (85%)
\$15,000–29,999	1 (5%)
\$30,000–49,000	2 (10%)
Citizenship	
Documented	2 (10%)
Undocumented	18 (90%)
Employment	
Employed outside the home, full-time	6 (30%)
Employed outside the home, part-time	4 (20%)
Homemaker	8 (40%)
Unemployed	1 (5%)
Other	1 (5%)
Highest education level	
Less than high school	15 (75%)
High school	4 (20%)
College graduate	1 (5%)
Caregiver duration, years	
Median (IQR)	4.0 (1.5–5.3)
Duration of consent/visit, minutes	
Median (IQR)	120 (97.5–120)
Location of visit	
Hospital	11 (55%)
Caregiver's home	8 (40%)
Other	1 (5%)

SD, standard deviation; IQR, interquartile range

experiences of primary caregivers of undocumented immigrants with ESKD who rely on EOHD.

METHODS

Study Design

The study comprises semi-structured interviews with primary caregivers ($N = 20$) of undocumented immigrants with ESKD that rely on EOHD. The study was approved through the multi-institutional review board of the University of Colorado, Anschutz Medical Campus. Participants provided written informed consent.

Setting and Participants

Eligible participants were English- or Spanish-speaking adults that were identified as the primary caregiver by the undocumented immigrant with ESKD that relied on EOHD in Denver, Colorado. Since February 1, 2019, undocumented immigrants with ESKD in Colorado receive standard thrice-weekly outpatient hemodialysis. Prior to that time, Denver Health

(DH), the safety-net hospital for Denver County, provided EOHD to an estimated 60 undocumented immigrants. The EOHD approach in Colorado is similar to that in other US states. To receive EOHD, an undocumented immigrant had to present to an ED and be critically ill (potassium > 5.2 , bicarbonate < 15 , oxygen saturation $< 90\%$ or an increase in baseline oxygen requirement, or signs/symptoms attributable to uremia). Patients who were admitted for EOHD stayed in the hospital overnight, received a second dialysis session prior to discharge, and repeated this cycle every 6–7 days. Our study used convenience sampling to recruit caregivers prior to the February 1, 2019 health policy change. Undocumented immigrants presenting to the hospital for EOHD received an information sheet (available in English and Spanish) and caregivers could then choose to participate.

Interview Guide

The interviews included open-ended questions (see the Appendix in Table 3) to understand the experiences of primary caregivers for undocumented immigrants with ESKD that rely on EOHD.

Data Collection

L.C. (principal investigator) identified eligible patients as they presented to the hospital for EOHD. The bilingual Spanish-speaking research assistant (C.C.) met with patients and provided the information sheet. Participants were interviewed one-on-one at their site of preference from June 28, 2018, to November 15, 2018. The semi-structured interviews were audio-recorded, transcribed, and de-identified. Recruitment of participants ended when we reached thematic saturation (i.e., no new themes emerged).

Analysis

We used thematic analysis and principles of grounded theory.^{6,7} Atlas.ti software (version 8.3.1) was used to systematically organize the data and perform open coding. To synthesize and contextualize data, two of the authors (L.C. and A.C.) independently read the transcripts and met regularly to discuss emerging themes, discrepancies, and alternative explanations. L.C. and A.C. reached consensus on themes with R.H. to ensure the themes reflected the full range and depth of the data.⁸ We pursued agreement through discussion when differences in interpretation arose. Investigator triangulation and member checking ensured that the themes reflected the full depth and range of the data.

RESULTS

Participants ($n = 20$) had a mean (SD) age of 46 (17) years, 13 (65%) were female, 18 (90%) were undocumented, all were primarily Spanish-speakers, and the median caregiving duration was 4 years (IQR: 1.5–5.3) (Table 1). Seven (35%) caregivers were adult children of the patient and the remaining were spouses. We identified five high-level themes: caregiver role,

Table 2 Themes and Subthemes with Illustrative Quotations

Themes and subthemes	Illustrative quotes
1. Caregiver role Providing emotional, physical, and economic support	<p>“In my role as companion and wife and because of the great love that I have for him, I am beside him. Supporting him in all areas even economically when it is possible.”</p> <p>“From working to earn money to maintaining the house to preparing the food...I have to do things myself.”</p>
Advocacy and care navigation	<p>“Moving him around, everything, I would give him his bath and take him to the bathroom. I would sit him down and get him up. Everything.”</p> <p>“I’m trying to find a solution that will help us with my dad so that he can receive treatment without having to suffer. Its difficult seeing him.”</p> <p>“The doctors had just gotten left the room. I stayed there with him because he had oxygen and he was restless and kept insisting he wanted to leave. Then he made a movement like he was going to throw up and that’s when I yelled for the doctors to come over. They ran over and quickly put a mask on him. I was rushed out of the room.”</p> <p>“My children and I are asking about kidney transplantation. My children say, ‘I’m willing to donate a kidney to my dad so he does not have to do that anymore’”</p> <p>“I think your immigration status should not be the reason you are treated differently. You are dealing with a person’s life. This disease is not like a cold we can treat at home. This is not minor. I know there aren’t that many resources or aid within the state.”</p>
2. Caregiver burden Anxiety related to patient and personal death	<p>“The fear I have is that we may lose him. That’s what we fear. It’s what concerns us most. It’s what my daughter says will happen sooner or later. What if something happens while he’s asleep, or while here at the hospital. That’s our worse fear”</p> <p>“There have been nights that I have not slept. I wake up and I touch him to make sure he is breathing. This is my fear.”</p> <p>“I’m afraid that if I died, I would not be able to provide for her. I sometimes think I will not be able to continue. That I’ll get sick.”</p> <p>“I fear leaving my wife alone; not being with her anymore. I do not know what would happen to her if I wasn’t with her. I’m talking about death.”</p>
Emotional exhaustion and personal illness	<p>“I’m afraid. I tell my mom every week when we go to the hospital that I do not know how things will go. We’ve seen people on dialysis that are okay and then suddenly things get complicated.”</p> <p>“I do not work because I want to be with my husband to prevent him from dying. I do not want my husband to pass away. That would be too hard for me. I feel terrible during dialysis but I do not say anything to him. I look at him to see if I can detect any symptoms.”</p> <p>“My daughter still has one more year left to graduate [crying] and when she saw my dad so sick, she told him to be strong so that he can see her graduate. I hope that happens. She’ll be the first to graduate. It’s hard because we would not want him to be gone.”</p> <p>“I’m most stressed when she starts feeling bad. Sometimes we go to the hospital in the middle of the night”</p> <p>“I’m also no doing good. I have pre-diabetes too. I never stop. Sometimes I do not even eat. We have to take care of him. When I get angry with him, I ask my son to take care of him so that I can rest. Sometimes I feel tired. Sometimes I get angry but not enough to leave him. He cannot walk and his hand does not work. Life is very sad for us.”</p> <p>“I get tired. I get stressed. My neck and shoulder hurt. I lie down and I cannot even sleep because I’ll be having to wake up to take my dad to the hospital again. One time he had a lot of water in his lungs in addition to pneumonia. They had to put him in the medical intensive care unit for 2–3 days. It was difficult. I think I’ve lost about 15 lbs.”</p> <p>“This week was very stressful for me and now I’m feeling it because I have high blood pressure, my neck hurts a lot.”</p>
Struggle with finances	<p>“I drag my leg. They say it’s a nerve sciatica problem in my leg, I tell her, ‘I’m old, I cannot do this’ but then I think, if others can do this, why cannot I? I can do it too.”</p> <p>“I cannot leave home without thinking about my mother. I cannot live my life. I cannot accept a friend in my life unless that person accepts my mom and her illness because my mom is my priority. It affects everything. Caring for her and always being aware of her. Sometimes it’s really sad because I feel helpless. It’s really stressful to see your mom go through this.”</p> <p>“I wasn’t bothered about anything before he was diagnosed with kidney failure. Never. He took care of everything. He had two jobs and paid the rent. My children were at school. After he was diagnosed with kidney failure, my daughter had to drop out of school to help us. Now he is sick and it has been two years since everything changed. Sometimes my daughter has money and she gives me money for medicine, for and electricity. Every eight days I make tamales to help pay for the medicine.”</p> <p>“He says, ‘how are we going to do this? To pay for everything. The car that breaks down.’ I tell him, ‘do not worry, we will take care of it. Do not you worry.’ is what we always tell him because if we worry him, he will get sicker and we cannot do that.”</p> <p>“My job is hard and I do not earn much. Last week I earned \$400 and I have to stretch it out to pay for everything for the month like food, electricity, and everything. I do not know how I’m going to manage now but if God helps me, perhaps I will be able to pay my rent and have money to eat. What can I do accept push forward. There’s no other thing to do.”</p>
Self-care	<p>“There was one time that I was very hungry and I had to beg a woman.”</p> <p>“We collect cans. We leave at 4 a.m. to collect the cans. He uses a lamp that he hangs on his body. We get the cans, crush them, and then come back home and I fix lunch or dinner. I started selling tamales too. One time, the police was about to take me with my icebox full of tamales. I told them not to take me and they left me but said I could not sell tamales anymore.”</p> <p>“You learn a lot about how to change your eating behavior and you become spirituality because you see this illness and it’s terrible. It was hard but I learned that you have to take better care of yourself.”</p>

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Table 2. (continued)

Themes and subthemes	Illustrative quotes
Redefining relationship	<p>"I was having headaches, and body pain but I went to my Zumba class because I had stopped going. This was the remedy for me. I feel bad leaving him alone but it is only one hour."</p> <p>"Sometimes we fight over nonsense but it's not worth it. It's not worth it to lose time on nonsense or arguments. We need to value taking care of yourself, that."</p> <p>"I never thought I would live this way. Taking care of him. I am older than he is. A few years older, so I never thought that I would be the one helping him. I thought I would need more help from him. He is the one that needs help from us."</p> <p>"This did not happen in the beginning but over time this affected our relationship. I like to be clear with people and tell them that my priority is my mom so I do not make other people waste their time. That has been the biggest change."</p>
3. Unpredictable emergency-only hemodialysis Acute episodes of illness that trigger emergency	<p>"He was so sick that he was unconscious. We called the paramedics and they said that his potassium was too high and his life was at risk. He was forgetting everything and not thinking well in the hospital. He said he was going to his grave."</p> <p>"My mom get nauseated, dizzy, and swollen. She rests so she can feel better. The first time she had an emergency visit, she was bleeding badly. Around 3 in the morning, we heard a loud sound. She told us earlier in the day that she could not sleep because she could not breathe. She sat in bed most of the night and finally fell asleep and that's when she fell down. She lost a lot of blood. Her face and hands were very pale."</p> <p>"I have taken my mom to the hospital several times when she was minutes away from dying. Once, I had to get her out of the house in my arms."</p> <p>"He was unconscious. He did not know who I was. That was one of the worst days. That day he said he felt dizzy and he needed help. He fainted and fell out of bed. My son called an ambulance and they told us at the hospital that it had affected his heart."</p> <p>"He said 'I feel really sick and I need you to come and take me to the hospital.' I noticed that he wasn't breathing well and I asked my cousin to bring him to where I work. My dad was really sick and I had to call an ambulance because they said that he almost had a heart attack."</p> <p>"They took him straight from the emergency department to the intensive care unit. His heart rhythm changes and they have to do something quickly when he needs dialysis"</p> <p>"They did not admit us because his potassium level was not high enough even though his urea toxin level was high. The nurse told me they could not admit him. Then they wanted to do a flu test and he did not want it. The nurse said, 'if you do not want the flu test then we will send you home and if you go home, you might die.' He would not be admitted for dialysis."</p> <p>"Yesterday I brought him here and he asked me to wait for him in case they decided to not admit him for dialysis. His face was very swollen and I said, 'how could they not take care of you?' The days they do not admit him are the worst days."</p> <p>"They offer dialysis only when it's an emergency and I think that is the saddest thing about this. This is a human life and in this case it's my mother and so this is really frustrating."</p> <p>"There are times when they tell him, 'You're not getting into dialysis today, would you like to go home?' That's sad for me, because he'll get sick sooner now."</p>
Stress when patient is denied dialysis	<p>"Those days in the hospital for dialysis are the days that I am hospitalized too, I am practically hospitalized too. I cannot work. I mean, I work a little during that dialysis time. I have a daily routine with work except the days she has dialysis. When we are at the hospital late its tough. The days that she needs dialysis, I do not go to work early, I stay with her until she wakes up and then drop her off at the emergency department. She updates me over the phone. Once she tells me she's connected to dialysis, I know the schedule and I try to be there when she is done with dialysis."</p> <p>"When she gets out of dialysis early, I have to get permission at work to come and pick her up at the hospital. Its tiring."</p> <p>"There are days when he is sick and she has to call work and say 'Let me off work' and they say 'It's not possible.'"</p> <p>"I know that every Tuesday, I have to take her to dialysis. Sometimes it's difficult because she used to do everything on her own and now I have to do it; I have a meeting at school because I'm part of the PTA; I have to postpone some things to be able to look after her."</p> <p>"I cannot work. I want things and I cannot have them. That's the most stressful thing. And the second thing is that I do not know how my mom is. When she's in the hospital or when I'm at school."</p> <p>"They told my mom that her fistula was not working. That's why her bleeding did not stop. She had to spend the day at the hospital getting her fistula fixed. That day I had to go to work at 6 in the morning and it was hard for me because I did not want to leave my mom at the hospital. I did not have any updates about what was going on at the hospital. I called work and told them I was going to be late. I was very tired because I had been awake the entire night. It was hard for me to drive because I was too tired."</p> <p>"I cannot go to sleep because I'd be keeping an eye on him, but then I'd start thinking about all sorts of things."</p> <p>"He wants me to be here before he leaves dialysis but I cannot miss work because they will going fire me. I left work twice and they told me that if I wanted to keep my job I had to be there."</p> <p>"I cannot go to sleep because I need to keep an eye on him."</p>
Impact on work and sleep	<p>"Once we get to the hospital and he's admitted for dialysis, I'd be like, 'Thank God.'"</p> <p>"I feel less stress when the hospital is going to take care of her. When she is discharged from the hospital, she's good. We all see it. Her illness does not affect her as much and she says 'I'm going to do the dishes'"</p> <p>"Yes, because Sunday, for example, is already a bit difficult. Monday is more difficult and the day she goes to dialysis because, as you say, when she first comes out of dialysis is when she can eat. Better without nausea or feeling bad, but she's there sometimes, this day she's out."</p>
Emotional relief after a session of emergency-only hemodialysis	
4. Effect on children	

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Table 2. (continued)

Themes and subthemes	Illustrative quotes
Dropping out or missing school	<p>“Last year, I missed school three times because of my mom’s illness. In previous years, I missed school quite a bit because my mom needed a interpreter at the hospital. So I missed a lot of school because I was helping my parents. After school, I help with everything. I do the housework. I help my dad clean the yard outside. Sometimes I have time to do my homework. I also call my mom between classes to see how she’s doing. I got in trouble at school for doing that.”</p> <p>“I was about to finish school that year but I could not do it. I was in 12th grade. I would like to return to school but I have not been able to. Perhaps in the future I will. If my dad could receive dialysis regularly, I would able to return to school.”</p> <p>“She was in college and she failed some classes and she did not want to go back again. I told her, ‘how will we manage with your dad and his dialysis?’ Just wait, because if he dies, we’ll figure a way to go back.”</p>
Psychosocial distress	<p>“My son worries a lot. ‘How is he doing, mom?’ I say, ‘good, son, he’s doing good.’ He’s a worrier. He also wants me to be there with him, and it’s not easy to divide myself in half.”</p> <p>“I wake up anxious to see my mom. To know that she is okay. I get ready to go to school and when I come back home I am happy because she is here when I arrive. When she is accepted to receive dialysis in the afternoon, I’m glad because I’m the one that picks her up from the hospital. There are times when my mom is sick and I am stressed and I cannot pay attention at school. I’m thinking about her and I do not pay much attention.”</p> <p>“We have three young girls. My daughter asks me, ‘is my daddy going to bring me a surprise?’ I tell her, ‘yes.’ She ask me, which one? I tell her, ‘he is your surprise.’ Then she says ‘I want to go to the hospital’ but she cannot go to hospital. My youngest wonders why her daddy is not home very much and she says, ‘I do not understand why my dad always has to go to that hospital.’ One night I had to bring my daughter to the emergency room and she said, ‘no, I do not want to be there, I do not want to be there for days like my dad.’ She’s the one that misses him the most. I hope that he does not get sick at night because it would be very difficult for me to bring them with me because a hospital is not for children.”</p> <p>“He sometimes feels that we do not understand his illness and he says mean things to me and to the children. My younger daughter said, ‘you were fighting.’ She saw everything. I do not want to talk to them about the fighting because I do not want them to hate him.”</p>
Children assuming caregiver responsibilities	<p>“My son scolds me when I buy foods high in potassium. He says, ‘why did you buy this? This is poison for my dad.’ Once, he threw 6 bananas in the trash. He says, they are good for us, but not for his dad and its not okay for him to even smell them.”</p> <p>“I was about 13 years old when she was diagnosed with kidney failure...and now I’ve started driving and I give my mom a ride to the hospital. When she has to go to the hospital in the afternoon, I take her. My sister cannot do it because she has 4 children.”</p> <p>“Sometimes my dad says that he feels like he cannot help himself. I tell him ‘well, you do not need to do that. You have helped us so long and now we need to help you, whenever you need that.’”</p> <p>“My daughter takes care of her dad. She is the one I trust with him when I leave the house. She watches over him, gives him lunch.”</p> <p>“Well, I’m the oldest daughter. I have the responsibility to look after him. I’m not going to let him die. I took that role after seeing that nobody was helping.”</p>
Juggling multi-generational caregiving of children	<p>“But my little girl, the smallest one, I feel terrible for her. She is the smallest and she needs more attention but sometimes I have to leave her with my older children. I have to leave her so that they can take care of her while I’m in the hospital taking care of him because when he leaves the hospital, he cannot walk.”</p> <p>“I was gone for three days while in the hospital with my dad. My son says ‘mom you were gone for three days and you said it would only be two.’ Its hard. The day I came back, my son had a school event to receive his supplies and meet his teacher. On my way home, he called and said, ‘mom, are you going to make it?’ He wanted me to be there. I said, ‘I’m coming.’ I went without any sleep and without a shower to school with him. After that I also had to go with my other child.”</p> <p>“I told my daughter, ‘I have to put money on a card for you so that you can call an Uber.’ We cannot take the bus because it arrives at the hospital to late. Then I pick her up from school and then we go back to the hospital.”</p>
5. Faith and appreciation Comfort in God	<p>“God takes care of us. We came to the US not knowing how to navigate things. We did not know anything and had to be strong and hold on to God’s hand. Its difficult. We did not know the streets that are one-way.”</p> <p>“God is always taking care of us. Like a brother he is always there with us. We have a loving God who gives us strength every day. We say, ‘do not worry. You will be fine.’ He was starting to feel depressed but with God’s help, we are supporting him. We cannot do it alone.”</p> <p>“I thank God for all the bad stuff that has happened to me because it made me mature. I now have better health and a better relationship with my mother.”</p> <p>“Every time I go to sleep, I ask God and the Virgin Mary to not let anything bad happen during the night. If he’s going to get sick, let him instead get sick during the day when my daughters aren’t there, because it would be very difficult to bring them with me.”</p> <p>“I would give her another life and she really deserves that and more, why? Because she’s the woman in my life, she’s the woman I chose and I do not regret it at all, on the contrary, I say, it’s good that God gives me these tests so that I can overcome them, why? Because I have to push forward and we are going to push for work with God’s help.”</p> <p>“Thank God He gave me strength because I do not think I could do it by myself.”</p> <p>“I always ask God to give me patience to take care of this man. God has given me so much patience.”</p>
Appreciation of healthcare	<p>“Everyone I know with kidney failure has gone to Mexico and does not live long. Even if they receive dialysis, they do not treat them the same like in here.”</p>

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Table 2. (continued)

Themes and subthemes	Illustrative quotes
	<p>"I thank the Lord that my loved one has this opportunity to receive the dialysis. In Mexico, he would probably not receive dialysis and he would not be with us."</p> <p>"I tell him, behave well with the doctors at the hospital because they are doing you a favor. Be grateful with them because they are taking proper care of you."</p> <p>"In Mexico, perhaps it would be more difficult. For people without resources that did not study, life with this illness would be difficult. I lived in a very small town in Mexico and a lot of people did not have money. They die at the hospital because they cannot pay."</p>

caregiver burden, unpredictable emergency-only hemodialysis, effect on children, and faith and appreciation of healthcare. See Table 2 for themes, subthemes, and illustrative quotations.

Caregiver Role

Providing Emotional, Physical, and Economic Support.

Caregivers identified assistance with activities of daily living and economic support as their main roles. A caregiver commented, "I feed him, sometimes he gets diarrhea and I change his diaper, bathe him, and change his clothes." Caregivers provided economic support to maintain the household or purchase medications: "I do the house chores. I make tamales to sell. I take care of my children. I take care of my husband because he cannot walk, bathe, or take care of himself. I give him his medicine and lay him down. Every day I devote myself to our home."

Advocacy and Care Navigation. Caregivers described advocating for the patient's well-being by helping to navigate care through communication with providers, appointment scheduling, and resolving social barriers: "Well, I tell him to do his best. I make him come to his appointments every time he has one. I have to keep an eye on him, because I feel that if I were not by his side he would not come to get dialysis."

Caregiver Burden

Anxiety Related to Patient and Personal Death. Caregivers worried that they would miss detecting important symptoms if they were not constantly at the patient's side. One caregiver described waking up in the middle of the night out of fear the patient had stopped breathing. Another caregiver describing leaving her job to stay at home to ensure the patient's well-being. Some caregivers reported enduring personal death anxiety regarding uncertainty of who will provide supportive care to the patient if the caregiver is the first to pass away.

Emotional Exhaustion and Personal Illness. Caregivers reported emotional exhaustion and expressed a sense of guilt for holding this sentiment. One caregiver reported emotionally coping in isolation: "Sometimes I'm scared and sad when she is suffering. I isolate myself. I stop at a park and cry. I can't do anything else. The other day, a police almost stopped me but I think he had pity on me." Many caregivers struggled balancing their emotional exhaustion with their own personal illnesses: "I have diabetes and I try to think, 'I'm not sick, I'm

well.' Sometimes I leave the house because I have too much stress. There are moments that are very difficult and I cry, scream, and shout. We have problems that give me headaches and body pain."

Struggle with Finances. Caregivers described challenges with household finances as the patient's ESKD progressed: "I didn't have to worry about anything financially. I didn't know how to pay bills and now I'm the one that takes care of bills. When my dad sees that mom and I don't have enough money [crying], well, I know he would like to help us but he can't." Respondents also reported relying on financial support from family members.

Self-Care. Caregivers reflected on how their caregiving role and experiential knowledge of ESKD has enforced better self-care behaviors: "After seeing the illness, I try to take care of myself. I go to the clinic; I check all my diabetes and kidney levels." Another caregiver described her increased self-efficacy: "I went to the hospital and made an appointment for stress and anxiety. I have to be healthy for my children and my mom. I was afraid to seek help but I have to ask for help."

Redefining Relationship. Spouse caregivers reflected on how ESKD changed their relationship with the patient, with more time spent in the home and reduced engagement in activities they once enjoyed. One caregiver said, "I miss her support. We would do the laundry together and we would go out more often. Now if I take her somewhere, we have to get back because she has dialysis. I don't have time to relax. I can't go on holidays either." Spouse caregivers also described intimacy issues: "His stomach has been cut. He's been cut all over. I can't touch him anymore. I am affectionate and loving, but we haven't been intimate despite sleeping together for many years."

Unpredictable Emergency-Only Hemodialysis Acute Episodes of Illness that Trigger Emergency.

Caregivers reflected on acute episodes of ESKD that prompted an ED visit: "I'm nervous and tense when he's not well. We were all in the kitchen and he got sick. His face was pale and I saw that he started to bend over and I said, 'let's go to the hospital!' I couldn't control my anxiety. When he needs emergency dialysis, he has headaches, body aches, and he

starts to shake.” Some caregivers recalled acute symptoms concerning for death: “I thought I was going to lose him that day. He started coughing and I sat him up. I went to the bathroom after he fell asleep but then I heard him cough and he had turned blue.”

Stress when Patient Is Denied Dialysis. Caregivers described emotional distress or frustration with the medical team when the patient was denied EOHD due to lack of hospital capacity and/or the absence of critical lab levels and vital signs necessary to qualify for EOHD: “The most stressful thing is seeking care and not receiving it. The doctor saw how my dad looked yet said that based on the studies he did not need dialysis. He said that my dad was just occupying a room. Imagine being told this? Do I leave him to die? Not a single doctor could help my dad. Not one. This was stressful and keeps me awake at night.”

Impact on Work and Sleep. Caregivers described sleep disturbance and inability to work. One respondent made the analogy of being hospitalized himself while witnessing the patient go through weekly EOHD. Employed caregivers reported exhaustion from their disrupted work schedules in combination with the patient’s EOHD schedule. Some caregivers face the challenge of choosing between maintaining their job for household income or providing supportive care.

Emotional Relief After a Session of Emergency-Only Hemodialysis. Caregivers described a sense of relief after the patient received EOHD because of symptom improvement and because patients were able to participate in activities at home: “When my mom receives dialysis, she feels better and takes better care of things at home. We can actually prepare food together.” Other caregivers noted a change in the patient’s affect after EOHD treatment: “He is very happy after he receives dialysis. He even stands up alone and tries to walk by himself. Those are the days that he is happiest.”

Effect on children

Dropping Out or Missing School. Spouse caregivers reported that their children had dropped out of school to work or provide caregiving: “My daughter had to drop out of school to help us after he was diagnosed with kidney failure. She was studying and had to stop to work. She wanted to keep studying but how will we pay for his illness? My other daughter also dropped out of high school to help us. I can’t get a job because it would mean leaving him alone.” Child caregivers also reported dropping out or missing school or delaying graduation to provide caregiving at home or to work.

Psychosocial Distress. Child caregivers described constant anxiety and sadness from unpredictable symptoms and their fear of losing their parent. They also described sadness and anger from witnessing the emotional tension that caused

parental discord. Spouse caregivers lamented that because of the illness, their children had grown up too fast and were unable to enjoy childhood: “My daughter was crying. We thought that he was going to die. It is really sad that we have to do this every week. My youngest daughter hasn’t enjoyed her childhood. She’s small. She’s always with me and helps take care of him. This has affected her though and she has changed. She has become very angry.”

Children Assuming Caregiver Responsibilities. Spouse caregivers described leaving their children as caregivers when they need to leave the house. They also described support from their children for language interpretation in the hospital and for transportation during EOHD: “Instead of me supporting him, my daughter has been the strong one. She is always looking out for us. Our daughter has been a strong girl and has supported us a lot. She takes him to the hospital and brings him back and never gets upset.”

Juggling Multi-Generational Caregiving of Children. Child caregivers who themselves have children described having to juggle caring for their own children with their parent. Often-times, providing care to the parent came at the expense of leaving their own children with older siblings or missing their children’s school events: “It is difficult when I have to go to the school and I also have to take her to dialysis. One time, for example, my little girl was in a dance performance so I had to drop her off at school and then drop my mom off at the hospital for dialysis. I then came back to school for the dance performance. Then back to dialysis and then back to school.”

Faith and Appreciation

Comfort in God. Caregivers described relying on God for emotional support, especially when facing a “bad experience.” Some caregivers also relied on God to take care of the patient’s well-being during the night and on the timing of the patient’s death: “It is important to have faith in the all-powerful God. He is the one that gives us life and he is the one that takes it away.”

Appreciation of Healthcare. Several caregivers described a deep appreciation for their care even though dialysis was offered on an emergency-only basis because it is not available in their home country. Caregivers also described the healthcare staff as attentive and approachable: “I can’t speak English or read but the doctors and nurses approach you and they are very attentive. They introduce themselves. They are really nice and friendly.”

DISCUSSION

Our study identified themes and subthemes that reflect the experiences of primary caregivers of patients receiving EOHD. We found that primary caregivers for patients with

ESKD who rely on EOHD encounter death anxiety as well as physical and emotional exhaustion. Caregivers described the impact of EOHD on children because either the spouse caregiver shared children with the patient or the caregiver was an adult child of the patient. In addition to psychosocial distress, EOHD had forced children to drop out or miss school. Nevertheless, caregivers found comfort in God and were appreciative of the healthcare they receive.

Our findings complement the literature describing high caregiving burden among caregivers of patients with ESKD who receive standard dialysis.⁹ Caregivers similarly feel overwhelmed while providing support with daily activities and advocate for the patient despite stress about their own health.¹⁰ This worsens their sleep and emotional and physical health.^{9, 11–13} Our study also confirms that caregivers use faith and spirituality to cope¹⁴.

Unique to the caregivers of this study is the added distress surrounding the immigration issues and EOHD process. Family members describe growing anxiety while observing the patient's progressive symptom accumulation to the incapacitating level needed to meet criteria for EOHD while knowing the risk of death is also rising. This caregiver stress is multiplied when the visibly ill patient is denied dialysis because they do not meet objective criteria. Caregivers describe the effect of this unpredictable process on their ability to work and their family dynamics. The inability of these undocumented patients to enroll in federal assistance programs places an additional financial burden on the caregiver and their children, who may drop out of school to fulfill responsibilities to the family.

Our findings on the experiences of caregivers were consistent with those reported by patients.⁵ Patients similarly described death anxiety, distress due to acute episodes of illness that trigger the emergency, stress when denied dialysis, relief after EOHD, and appreciation of the healthcare system.⁵ Clinicians who provide EOHD also described emotional exhaustion, perceived lack of control over EOHD criteria, physical exhaustion from overextending themselves to bridge care, and inspiration toward advocacy¹⁵. This study adds to the growing body of literature which shows that EOHD is below the recommended standard of care for patients with ESKD. Compared with standard hemodialysis, EOHD is associated with higher mortality^{3, 16}, greater healthcare utilization^{3, 16}, higher complication rates¹⁷ and healthcare system costs¹⁶, more physical and psychosocial distress for patients^{5, 18, 19}, higher rates of burnout and emotional exhaustion for clinicians¹⁵, and greater caregiver burden. These studies show that states using EOHD rather than standard hemodialysis for undocumented immigrants are providing less efficient care with worse clinical outcomes, at a much higher cost. Our study suggests that EOHD also imposes substantial health effects and social costs on caregivers and their families, due to lost employment and educational opportunities.

A recent review of the emergency Medicaid language across the USA showed that several states (e.g., Arizona, Washington, Colorado) have modified their emergency Medicaid language to include ESKD in the definition of an emergency medical condition.^{2, 20} Federal officials defer to states to define what constitutes a medical emergency. In states that have not modified their emergency Medicaid definition, and where there are no other available resources (e.g., private health insurance paid through charitable support, county-funded or safety-net hospital funded free-standing dialysis centers), undocumented immigrants rely on EOHD. Clinicians across the country in states with high numbers of undocumented immigrants have advocated for a similar health policy change to provide standard dialysis to patients regardless of their immigration status^{4, 21–27}.

Limitations

Primary caregivers were recruited from a single academic safety-net center. The generalizability of our findings is uncertain because access to standard dialysis and EOHD protocols vary throughout the country. Additionally, our aim was to describe the diversity and depth of participant perspectives, and cannot ascertain the frequency of opinion. Our study, however, is the first to describe the experience of primary caregivers of patients that rely on EOHD.

CONCLUSION

Primary caregivers of undocumented immigrants with ESKD who receive EOHD suffered high levels of stress. They described the unpredictability of EOHD and its adverse consequences for the patient, the caregiver, and the family, including serious effects on their own children. The distress experienced by primary caregivers and families of undocumented immigrants who receive EOHD, along with the worse clinical outcomes and higher costs associated with EOHD, indicates that policy reform is needed to provide undocumented immigrants with ESKD access to standard dialysis.

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APPENDIX

Table 3 Interview Guide

1. What is your role in supporting or caregiving for your friend/family member with kidney failure?
2. Think back to when your friend/family member was diagnosed with kidney failure, how is your life different now than it was then?
3. Can you describe a regular day in your role supporting your friend/family member with kidney failure
4. What does a good day look like?
5. What does a bad day look like?
6. What has been most distressing?
7. What are your greatest concerns or fears?
8. What do you value most about your role in supporting your friend/family member with kidney failure?