Title

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Journal
Progress in Transplantation, 30(2)

ISSN
1526-9248

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Publication Date
2020-06-01

DOI
10.1177/1526924820913520

Peer reviewed

Research

PROGRESS in TRANSPLANTATION

Progress in Transplantation
2020, Vol. 30(2) 76-87

DOI: 10.1177/1526924820913520
journals.sagepub.com/home/pit
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Recommendations for Systematizing Transplant Education Within a Care Delivery System for Patients With Chronic Kidney Disease Stages 3 to 5

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Abstract

Context: Early tailored transplant education could help patients make informed transplant choices. **Objective:** We interviewed 40 patients with chronic kidney disease (CKD) stages 3 to 5, 13 support persons, and 10 providers at Kaiser Permanente Southern California to understand: (1) barriers to transplant education and (2) transplant educational preferences and recommendations based on CKD stage and primary language spoken. **Design:** A grounded theory analysis identified central themes related to transplant education barriers, preferences, and recommendations. **Results:** Barriers included confusion about diagnosis and when transplant may be necessary, concerns about transplant risks, families' lack of transplant knowledge, financial burdens, transportation and scheduling, and the emotional overload of chronic illness. Hispanic and Spanish-speaking participants reported difficulty in understanding transplant education and medical mistrust. Recommendations included providing general education, earlier introduction to transplant, wait-listing information, transplant education for support persons, living donation education for patients and potential donors, opportunities to meet living donors and kidney recipients, information on the benefits of transplant, recovery, and available financial resources, flexible class scheduling, online and print resources, and more provider follow-up. Spanish-speaking and Hispanic participants recommended using bilingual educators, print, video, and online resources in Spanish, and culturally responsive education. Patients with CKD stages 3 to 4 wanted information on slowing disease progression and avoiding transplant. **Conclusion:** Increasing access to culturally responsive transplant education in multiple languages, pairing appropriate content to the disease stage, and increasing system-wide follow-up as the disease progresses might help patients make more informed choices about transplant.

Keywords

transplant donor, deceased < body regions, transplant donor, related < body regions, transplant donor, anonymous < body regions, kidney transplant recipient < body regions, education, health-care quality, access, and evaluation

Introduction

About 30 million Americans are living with chronic kidney disease (CKD),[1] a progressive loss of kidney function categorized into stages defined by the level of glomerular filtration rate (GFR). Glomerular filtration rate can decrease from stage 3 (GFR = 30-59 mL/min) to stage 4 (GFR = 15-29 mL/min) to stage 5/end-stage renal disease (ESRD; GFR $\leq$ 15) over time.[2] Patients who progress into stage 5/ESRD require either kidney transplant or regular dialysis treatments. Although some patients maintain reduced kidney function for an extended period,[3] others advance quickly, particularly in the later stages.[2] A 10-year study of patients with CKD stage 3 found that about 50% ultimately developed ESRD.[4]

Living kidney donor transplant (LDKT) is the optimal treatment for ESRD,[5,6] with patients who receive preemptive transplants living longer than patients remaining on dialysis or

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receiving transplants.[7] Unfortunately, LDKT rates have declined by 12% since 2004.[8] Preemptive transplants in 2017 only comprised 1.4% of LDKTs.[9]

Both the Organ Procurement and Transplantation Network and American Society of Transplantation Consensus Conference recommend that transplant education begins in CKD stage 3 to help patients decrease their wait-list time and identify a living donor.[2,10] However, mode, quality, delivery method and timing, and comprehensiveness of transplant education for patients with CKD stages 3 to 5 differs.[11-13] If patients are educated prior to ESRD, then patients could potentially receive a preemptive transplant, which offers higher patient survival, improved quality of life, and lower costs.[14]

Kaiser Permanente Southern California manages the care of nearly 65 000 patients with CKD stages 3 to 5. Kaiser Permanente Southern California's fully integrated care management program and diverse membership offer a unique opportunity to study the transplant educational preferences of patients with CKD stages 3 to 5. Thus, we conducted interviews with patients with CKD, support persons, and providers at Kaiser Permanente Southern California to understand their (1) barriers to interest in learning about and pursuing transplant and (2) general transplant educational preferences and recommendations by CKD stage and primary language spoken.

Methods

Participants and Recruitment

Kaiser Permanente Southern California has approximately 6000 patients with CKD stages 3 to 5 who have seen a nephrologist in the last 18 months. Of these, 52% are white, 24% Hispanic, 15% black, and 9% Asian. The majority, 67%, have CKD stage 3, with 19% in CKD stage 4, and 14% in ESRD. Since 2017, only 225 patients have received a transplant, with 66 receiving an LDKT.

To be eligible for this study, patients had to be 18 years or older, diagnosed with CKD stage 3 to 5, with no known contraindications for transplant. Estimated GFR, CKD stage, the presence of any factors that might contraindicate future renal transplant, body mass index, status of comorbid health conditions, and status of transplant evaluation were assessed using medical record review. Patients were recruited in person, by flyer, or by telephone within Kaiser Permanente Southern California system.

Support persons were referred by participating patients and recruited using snowball sampling. Support persons also had to be 18 years or older and not to be a paid care aide or health-care proxy.

All participants received a US$25 gift card, and those who required transportation assistance for interviews received a US$10 transportation voucher. Providers were not compensated. Protocols were approved by Kaiser Permanente Southern California's (11118, 111195) and UCLA's (17-001171) institutional review boards.

Data Collection

Structured interviews were conducted and audio-recorded at the individual's primary medical center or by phone by a trained facilitator following a detailed interview guide in English or Spanish. Interviews lasted 30 to 60 minutes. Patients and their support persons were asked about their transplant educational needs and experiences, gaps in and barriers to receiving transplant education, and recommendations for improvement. Providers were asked about their current education practices, what LDKT education they give to patients, and their perspective on barriers and facilitators present when educating patients about transplant.

Analysis

Using a Grounded theory study design,[15] NVivo qualitative analysis software was used to code major themes and subthemes. The research team reviewed the codes and determined the themes *a posteriori*. An independent team developed a preliminary coding scheme based on the interview guides, which was then fine-tuned to mirror the themes from Nvivo. Finally, the transcripts were recoded to ensure the complete capture of themes and variance among subgroups.

Results

Forty patients with CKD stages 3 to 5 (70% CKD stage 3; 5% CKD stage 4; and 25% ESRD), 13 support persons, and 10 transplant coordinators and social workers were interviewed (Table 1). Patients were predominately Hispanic (42%) and white (25%), and 28% were primarily Spanish speaking.

Perceived Barriers to Transplant

Patients, support persons, and providers reported multiple barriers to transplant (Table 2) including confusion and overwhelm about the CKD diagnosis, fears about transplant, financial concerns, and difficulty attending education sessions and maneuvering through the health-care system.

Confusion about CKD and its impact and when transplant might be necessary. Many patients with CKD stages 3 to 4 expressed surprise and confusion about their diagnosis and treatment. A patient with CKD stage 3 shared, "I was very surprised with the diagnosis [. . .] up until that point I had no idea there was any problem."

Patients and their support persons felt that they did not understand when transplant might be necessary. One support person asked, "I don't know what is the progression or the stage [*sic*], what is the difference between stage 3 and stage 4, that kind of thing, and what would make a person qualify, in need of a kidney transplant?"

Confusion about how to get wait-listed. Patients were confused about the process of transplant evaluation and how to get on the wait-list. A patient with CKD stage 5 asked, "I wish I would

Table 1. Participant Demographics.

Characteristics	Patients, N (%)	Support Persons, N (%)	Providers, N (%)
Total participants	40 (100)	13 (100)	10 (100)
Gender			
Female	19 (47.5)	7 (54)	
Not reported	6 (15)	2 (15)	
Language			
English	31 (77.5)	7 (54)	
Spanish	9 (22.5)	6 (46)	
Race/ethnicity			
White	9 (22.5)	4 (31)	
Hispanic	20 (50)	2 (15)	
African American	5 (12.5)	1 (8)	
East Asian/Pacific Islander/other/unknown	6 (15)	6 (46)	
Chronic kidney disease stage			
Stage 3	28 (70)		
Stage 3a	16 (40)		
Stage 3b	12 (30)		
Stage 4	2 (5)		
Stage 5/ESRD	10 (25)		

Abbreviation: ESRD, end-stage renal disease.

know what is the process, if that day ever comes for me, what do I have to do? Because I have no idea."

Lack of transplant knowledge by family/friends needed to support. All patients commented that their support networks lacked transplant knowledge and an understanding of what support they needed as a patient. One patient with CKD stage 5 stated,

> My mom doesn't understand much, but it's too hard for her anyway. She's going into Alzheimer's and dementia so that doesn't work. And my son does whatever he can, but he can always learn a lot more.

Lack of knowledge about appropriate living donors and fears about risk to living donor. Providers noted that patients lack knowledge about who would make a good living kidney donor. In the words of 1 provider, "I don't think people know who potential donors are, like who to pick and why family and siblings are the best." (Provider)

Patients brought up fears of risks to potential living donors, particularly that they would experience kidney failure in the future and need a kidney transplant themselves. A patient with CKD stage 4 acknowledged, "Well, my thing was, my daughter was interested in getting tested. But see, it's hereditary in our family, so it's like, huh. That's kind of—what if she needs a kidney later?"

Fears about possible risks of transplant. Patients and their support persons mentioned fears about the risks to the recipient, specifically possibly death or graft rejection. One patient with CKD stage 5 said, "Death. That's the big one. Or that my body rejects [the kidney]. Those things scare me."

Fears of being a burden. Patients stated worries of becoming a burden on their families by either needing support in transplant recovery or a living kidney donor. A patient with CKD stage 3 shared, "[. . .] I think when the time comes maybe, I wouldn't want to burden them with that now."

Financial burdens of ESRD and transplant. Patients, support persons, and providers noted that financial circumstances or concerns about transplant and medication expenses often posed a barrier. One patient with CKD stage 5 stated,

> I'm 51 and I haven't been able to go back to work, and that's very, very um, that's one of my things—I got two kids that are going to start college this fall, and money is just getting really tight. Social security ain't cutting it for me. I used to be the main breadwinner in my household, now I'm not, I can't function.

Transportation and scheduling challenges. Many patients revealed difficulties in attending transplant education classes due to scheduling conflicts with work and challenges getting transportation to the class. A patient with CKD stage 4 stated, "The actual taking time off of work for the class was a challenge."

Difficulty using interpretive and medical services for Spanish speakers. Patients who primarily spoke Spanish noted difficulties accessing interpretive and medical services. A patient with CKD stage 3 mentioned, "[. . .] with an interpreter, a lot of times they get words confused." A support person stated, "I think that when there is a translator, like for them as men, it is different than women, even though there is a translator they do not take things seriously."

Table 2. Transplant Barriers and Patient, Support Person, and Provider Preferences and Recommendations.

Barrier	Preference/Recommendation
Confusion About Chronic Kidney Disease (CKD) and Its Impact and When Transplant Might Be Necessary	Provide an Earlier Introduction to Transplant Education With a Prevention Focus
"I didn't feel like this was helping me a lot or any, the doctor just kept telling me 'you're gaining weight, you're gaining weight' but he wasn't telling me it was like from water, not water but from fluids and stuff [. . .] (CKD Stage 5 Patient) "I didn't take it seriously at first because I felt no symptomatic situation, you know. Then it got to a point where my kidney function was degrading [. . .] that kind of woke me up a little bit." (CKD Stage 5 Patient) "I was very surprised with the diagnosis [. . .] up until that point I had no idea there was any problem." (CKD Stage 3 Patient) "I did not know that it was renal disease and why, what causes it." (CKD Stage 5 Patient) "[. . .] we didn't even realize that he had problems with his kidneys until his doctor [. . .] he explained to us and asked us if I knew what was going on with my husband." (Support Person) "Uh, so a kidney transplant, does it depend on your stage or is it better that the patient is in stage 2 or in my case stage 3, would it be better to start with a transplant?" (CKD Stage 3 Patient) "Um, at what stage would I need to get a transplant?" (CKD Stage 4 Patient) "I wish I would know what is the process, if that day ever comes for me, what do I have to do? Because I have no idea. People tell me you need to get to the hospital right away, and you have to be prepared, and all this, but I don't know any official details about all that." (CKD Stage 5 Patient) "I don't know what is the progression or the stage [*sic*], what is the difference between stage 3 and stage 4, that kind of thing, and what would make a person qualify, in need of a kidney transplant?" (Support Person)	"And you don't want to scare them, but you just kind of want to educate them." (CKD Stage 5 Patient) "I would want to learn how to prevent getting a transplant. I would not like to get to the point where I need a transplant, I would want to recuperate before getting to a transplant." (CKD Stage 3 Patient) "Basically, they are telling me that I am fine but yes, it would be good for them to give me information [about transplant]." (CKD Stage 3 Patient) "What I think would be most helpful is maybe how to go about getting on a list, testing family members if they're interested in donating a kidney, things of that nature. I think but basically just the steps as far as like, what would step 1 be, what's the process basically." (CKD Stage 3 Patient) "[. . .] If they are in stage 3, offer a class to them about living donation and transplant . . . just so they have the knowledge." (Provider)
Confusion About How to Get Waitlisted	Provide Education on How to Get on the Transplant Waitlist
"I want to know, if I get placed on the list, how long will I have to wait? Or is it even worth getting on the list?" (CKD Stage 3 Patient) "I wish I would know what is the process, if that day ever comes for me, what do I have to do? Because I have no idea." (CKD Stage 5 Patient)	"What I think would be most helpful is maybe how to go about getting on a list, testing family members if they're interested in donating a kidney, things of that nature. I think but basically just the steps as far as like, what would step 1 be, what's the process basically." (CKD Stage 3 Patient) "I want to know, if I get placed on the list, how long will I have to wait? Or is it even worth getting on the list?" (CKD Stage 3 Patient)
Lack of Transplant Knowledge by Family/Friends Needed to Support	Provide General Transplant Education Geared Toward Family and Friends
"My mom doesn't understand much, but it's too hard for her anyway. She's going into Alzheimer's and dementia so that doesn't work. And my son does whatever he can, but he can always learn a lot more." (CKD Stage 5 Patient) "I think when if it's my time I would want my immediate family to be educated on it, just to be aware, especially my children." (CKD Stage 3 Patient)	"I feel that, any classes I could take, you know, as the person who would want to help her, if there were classes I could learn more, I would be willing to sign up for any and everything. I mean, I could probably go online, and learn stuff, but . . . some of it is too technical to explain, and I guess being visual, and trying to understand, it would need to be in English—in language I could understand." (Support Person)

(continued)

Table 2. (continued)

Barrier	Preference/Recommendation
Lack of Knowledge About Appropriate Living Donors and Fears About Risk to Living Donor	Provide More Living Donor Transplant Information for Patients and Support Persons
"I don't think people know who potential donors are, like who to pick and why family and siblings are the best." (Provider) "I had a patient ask me if his 68 year old sister who is a breast cancer survivor could be a candidate. I can't really give that information, but we never know when cancer regrows and she's 68 so that is not a realistic choice. I mean, maybe there should be some information or a flyer with who is a realistic candidate, because that is not a realistic candidate." (Provider) "There's also a fear where if a family member wants to give you one of their kidneys, there's that fear of their health. So I don't think I'd be open to that. I don't think I'd want to do anything like that for my family." (CKD Stage 3 Patient) "Well, my thing was, my daughter was interested in getting tested. But see, it's hereditary in our family, so it's like, huh. That's kind of—what if she needs a kidney later?" (CKD Stage 4 Patient) "I want to stay away from I guess the living donors, and go for the deceased donor—I tried already with my brother, and my brother was a match—he went through the whole process and everything, but because we have diabetes that runs in the family, they told him it's better if he not give a kidney, because what happens if he gives me a kidney—which he could—but later down the line, then he develops some kind of kidney disease? He'd be left with only one kidney. And I didn't want to do that to my brother. So I said I'll wait for a deceased kidney." (CKD Stage 5 Patient) "Yeah, she was willing to do it, and she would probably be willing to give me a kidney. But, you know, she's only a year younger than me, do I really want to impact her life that way?" (CKD Stage 3 Patient) "We have patients who are relatively young, who have spouses who are healthy, but when we bring up living donation they get really upset. Maybe provide more statistics to them as far as the risk factors, both immediate risk factors and then if there's any long-term risk factors." (Provider) "The majority of my patient population here—it's a whole family already affected by kidney disease. So when I'm talking about exclusion criteria for donors, and there's a hereditary kidney disease in the family, or diabetes or something. They don't feel it would be fair if—let's say somebody younger is approved—they know that down the line they are probably going to need a kidney transplant themselves, so they don't want to deprive them." (Provider)	"I think risk is something that I would want to know more information on [. . .] I think that that's a little bit lacking in this material . . . not only for the recipient but for the donor as well." (Support Person) "Yeah, I mean, gear it toward your friends, and family members, something for your living donors to read or watch." (CKD Stage 5 Patient) "These complacencies of folks who are on the waitlist and are sort of just sitting on dialysis . . . all of a sudden for them to get some information a month at a time can certainly remotivate them. Plus they'd get the correct information, perhaps within that information could be maybe some tips on how to share that need with family and friends." (Provider) "I would love to hold an evening class on donor information on a quarterly or biannual basis. I would contact my patients who have been approved and are on the waiting list and let them know that if they have anyone out there who is remotely interested in gaining more information living donation, I will have an hour class going over some of the facts and details dispelling some of the myths of donating one of your kidneys." (Provider) "I just think that a really good 15-minute video on how to talk to/how to approach someone to be a donor and another one who's a donor and people's experience on being donors." (Provider) "For me personally, talking to someone, or having a discussion in a group is more beneficial than sitting in front of my computer reading about it." (CKD Stage 3 Patient) "Some of the classes were in big groups, and some of them were in small groups, I think limiting it to like, five patients, and having more hands-on—more one-on-one . . . [would be better]." (CKD Stage 4 Patient) "An actual person that has donated a kidney would be good . . . They're the ones that can share that it's not that bad. 'I had these three incisions in my back, they took out my kidney, I was in the hospital for two or three days, and I'm out, and I'm back to work in three weeks.' I think having an actual person who has gone through the experience would be a good tool to include in the education." (Provider) "We have patients who are relatively young, who have spouses who are healthy, but when we bring up living donation they get really upset. Maybe provide more statistics to them as far as the risk factors, both immediate risk factors and then if there's any long term risk factors." (Provider)
Fears About Possible Risks of Transplant	Provide Education on Benefits of Transplant and Recovery
"Death. That's the big one. Or that my body rejects [the kidney]. Those things scare me." (CKD Stage 5 Patient) "Well, first of all, if you were to have a kidney transplant there's no guarantee it's going to work, so there's always that fear." (CKD Stage 3 Patient) "My biggest fear is just the body rejecting it." (Support Person) "I guess another question is what are the complications and the risks, involved in a kidney transplant? My wife mentioned that kidneys might be rejected. What are other complications and problems that can occur over time?" (Support Person)	"Well, I'll tell you when Dr. X puts on the workshops that he does [. . .] he does a very thorough job, not only does he use the doctors that work with him, his staff, but he includes a lot of lay people that come to the meetings that need donors or recipients of kidneys. So those are worth their weight in gold as far as I'm concerned, I mean you learn a lot from these people." (CKD Stage 5 Patient) "In the classes they always have other people like the nutritionist, the pharmacist who was way more helpful than I ever thought a pharmacist could be—the social workers, liked having all of them participate, it was really helpful." (CKD Stage 3 Patient) "You can't ask questions if you're reading online, but if you have somebody immediately there, and if they have people you can talk to, who are getting ready for a transplant, or after they've gone through a transplant, that's helpful to me too, so I know what to expect." (CKD Stage 3 Patient)

(continued)

Table 2. (continued)

Barrier	Preference/Recommendation
Fears of Being a Burden	Provide Education on Benefits of Transplant and Recovery
"[. . .] I think when the time comes maybe, I wouldn't want to burden them with that now." (CKD Stage 3 Patient)	"I know they go through tests to make sure that the organ that they're giving up, I know they go through a class themselves, and I know they're giving them the probabilities and the risks, and I know that it's—you have a better chance of acceptance from a living donor that's related to you than a deceased, or even a living donor that's not related to you versus a deceased [. . .] I know these things because they give it to you when you take the class [. . .]" (CKD Stage 3 Patient) "If I could get a transplant? Yes. It would be easier for me to do things. I won't get as tired to just sweep or take a couple walks around the mall or something. And with a transplant I can do a lot more, and travel, maybe." (CKD Stage 5 Patient)
Financial Burdens of ESRD and Transplant	Provide More Content About Financial Resources to Transplant
"I'm 51 and I haven't been able to go back to work, and that's very, very um, that's one of my things—I got two kids that are going to start college this fall, and money is just getting really tight. Social security ain't cutting it for me. I used to be the main breadwinner in my household, now I'm not, I can't function." (CKD Stage 5 Patient) "[. . .] my concern is, with the numbers of medications that I hear that she'll have to take, once she's had the procedure, that it might be expensive so you know the medications might be expensive." (Support Person) "I think financial does have an impact on their transplant, especially maintaining after, especially if they don't go back in the workforce; they lose their insurance, their employment, their kidney starts failing because they can't afford the medications, or they can't access any help. And sometimes the copays for the tests for workup is already sky-high." (Provider)	"People don't want to lose their job so they don't want to take off to do the workups. It happens all the time. I tell them 'Whenever you are here in a medical center doing a test, get a hold of me so that I can see if there is anything more that you can do while you are here." (Provider) "And also, financially, how is it going to get paid and all of that, right?" (Support Person) So if, is there a way that, if transplants are cheaper than dialysis, is there a way that you can pass legislation to get it more than three years? Because it would seem like you would be offsetting the expense of dialysis which the government does pay for." (Support Person) "How much it costs, you would need to know." (Support Person) "[. . .] I still want to know how much. How much the insurance is going to pay?" (CKD Stage 5 Patient) " . . . if I can't get the medication, diet and exercise alone aren't going to do it, at least I don't think they are going to do it. We need some stop gap measure; [. . .] I'm not saying give me the medication for free, I'm saying give to me at the discounted rate that you're giving it to me [already]." (CKD Stage 5 Patient)
Transportation and Scheduling Challenges	Offer In-Person Classes With Other Online Learning Options
"I can't really make [the classes] because of their schedule and my life schedule; it's hard to get to the classes" (CKD Stage 3 Patient) "The actual taking time off of work for the class was a challenge." (CKD Stage 4 Patient) "[. . .] if I have to come in to see you guys, I have to arrange transportation, and the closest place for me isn't that close." (CKD Stage 5 Patient)	"[. . .] possibly an online class . . . if I could do it on my own schedule, which would work." (CKD Stage 3 Patient) "A preferred format would be if I could either make an appointment and get it directly with the doctor because that's on a timeframe I can make . . . " (CKD Stage 3 Patient) "All of this information that they give someone, it is good, because they can learn, I think that if they have a question or someone gets stuck, that is why they have phones or ways to have people help you, to ask help now. More than anything to ask for help because one wants to learn more." (Support Person) "I think videos would be good. Written materials, sometimes, especially if it's thick . . . they kind of lose interest. So much reading to do, and it's just going to go in the pile of whatever junk they have. So, I think a video would be more effective." (Provider)

(continued)

Table 2. (continued)

Barrier	Preference/Recommendation
Difficulty Using Interpretive and Medical Services for Spanish Speakers	Make Educational Resources Available in Spanish and Classes Taught by Bilingual Educators
"Like for example, with an interpreter, a lot of times they get words confused." (CKD Stage 3 Patient) "I think that when there is a translator, like for them as men, it is different than women, even though there is a translator they do not take things seriously." (Support Person) "[. . .] sometimes I cannot communicate with the doctors, it is not easy to get help." (Support Person) "For someone who speaks Spanish, and comes to Kaiser, or any other place, and they have limited information in Spanish—I think they would find it difficult. Because I know where I go and do this dialysis, there are a couple of people who speak very little—almost no English. And they're going through the transplant procedure too. And they a lot of times have to take like a niece or a neighbor or something, so they can get it translated, because a lot of the people who give these classes, they just speak English." (Support Person)	"I think the DVDs [should be in Spanish] because there are people that might not be able to read Spanish or it is more about language, so the DVD would be more appropriate because it is more visual." (CKD Stage 3 Patient) "Well, the only thing is that if they are going to send us brochures or something, that they send them in Spanish [. . .]" (CKD Stage 3 Patient) "[. . .] if they gave it to us in English we would ask one of our children to read this and that when they have free time, they can explain it to us. But if it was in Spanish, one of us could read it and realize." (Support Person) "It would be better to have a set course of materials that is already translated into the other language, a video maybe that is for everybody." (Provider)
Hispanic Patients' Medical Mistrust and Specific Concerns About Risks for Living Donor	Help Providers Give Culturally Sensitive Education
"Well yes, simply, that one as a Latino does not believe what people say but simply like when he started with the insulin, he would say, no, there is no cure, you are going to die." (Support Person) "I would say a big part of it is cultural. A lot of patients we see already have adult children, have grandchildren, and they don't want to move forward and have anyone in their family exposed to that risk." (Provider) "Especially among the Hispanic community, it seems like no one wants to put their family at risk, to whatever might lie ahead related to actually donating. We try to reassure them that look, the transplant center . . . they're going to go above and beyond and make sure it would be a safe transplant . . . but for a lot of them, it doesn't seem to really make too much of a difference." (Provider)	"Education for potential donors really needs to be based on the listener, and if they do come from particular ethnicities and perhaps in their cultures they have different ideas on the body and donating, those can be addressed." (Provider)
Primary Responsibility to Pursue Transplant on the Patient	Increase Support for Patients Post-Class
"Well, the whole thing is overwhelming [. . .] Because I haven't even thought about considering transplant [. . .]" (CKD Stage 3 Patient) "I think that handing someone a huge booklet of things at a time when they're most devastated is just, almost an insult. It's like, my heart is broken, with this chronic illness, my family is a complete mess, and now you hand me a package and tell me to go to Santa Monica Blvd and have dialysis at 7 AM." (CKD Stage 5 Patient) "What I've seen at other sites, it's totally on the patients—they put this responsibility on the patients. It's your responsibility to contact the transplant coordinator to schedule one on one meetings." (Provider)	"For me, you know, follow up. And I think, because you're looking at doing some education, and, it would be done in a six-month period, then maybe six months from that time, follow up, to see if it was beneficial, "do we need to send you something else," just, just to keep in touch. (CKD Stage 4 Patient) I think there has to be a more individual understanding of what to do next, and who will be there for you. And really be cradled during that time, for a period of time." (CKD Stage 5 Patient) "But I think as time goes by we should be in contact with someone that, like that class we had, you need to come in and let's do a review, a refresher course on what should be done, based on the last reading because one of the things that they did, based on the last kidney reading, this is what . . . it was like a number, she had a certain number, based on the last labs and stuff like that, and based on the number this is what we recommend that you should be doing. This is the kind of thing that she probably needs to be following up every 18 months or so." (Support Person) "I think the biggest hole is just to follow up once these people have been placed on the waiting list and approved . . . I think following up by the coordinator to say 'Let's see a year down the road or six months to say okay you've been approved for kidney transplant, what are you doing as far as potential living donors, is there anyone out there at all—have you talked to family, have you talked to friends' . . . I think for a coordinator to follow up and make that phone call would probably be very important." (Provider) "But if we had better follow-up, we would probably get more people that we would start [transplant education] faster." (Provider)

Abbreviation: ESRD, end-stage renal disease.

Hispanic patients' medical mistrust and specific concerns about risks for living donor. Hispanic patients and support persons noted specific concerns about LDKT and medical mistrust. A support person said, "Well yes, simply, that one as a Latino does not believe what people say but simply like when he started with the insulin, he would say, no, there is no cure, you are going to die."

Primary responsibility to pursue transplant on the patient. Patients, support persons, and providers agreed that a major barrier was an expectation that patients could learn about transplant on their own. One patient with CKD stage 5 said,

> I think that handing someone a huge booklet of things at a time when they're most devastated is just, almost an insult. It's like, my heart is broken, with this chronic illness, my family is a complete mess, and now you hand me a package and tell me to go to Santa Monica Blvd and have dialysis at 7 AM.

Transplant Education Preferences and Recommendations

Key recommendations for improvement included expanded educational content in certain CKD and ESRD areas and for different audiences, providing transplant education earlier, and improving access to educational resources.

Provide an earlier introduction to transplant education with a prevention focus. Most patients expressed a desire to get transplant education along with the information about how to prevent ESRD if possible. A patient with CKD stage 3 stated, "I would want to learn how to prevent getting a transplant. I would not like to get to the point where I need a transplant, I would want to recuperate before getting to a transplant."

Provide education on benefits of transplant and recovery. In response to the barrier of potentially being a burden to family and friends, patients recommended providing more education on the benefits of transplant and recovery and how the transplant could positively affect their quality of life. A patient with CKD stage 5 related,

> If I could get a transplant? Yes. It would be easier for me to do things. I won't get as tired to just sweep, or take a couple walks around the mall or something. And with a transplant I can do a lot more, and travel, maybe.

Provide education on how to get on the transplant wait-list. Patients in all stages expressed a desire to better understand the process to get on the transplant wait-list. From a patient with CKD stage 3,

> What I think would be most helpful is maybe how to go about getting on a list, testing family members if they're interested in donating a kidney, things of that nature. I think but basically just the steps as far as like, what would step 1 be, what's the process basically.

Provide more content about financial resources for transplant. One major concern for patients was the financial burden of CKD and of potential transplant. Participants recommended providing additional information about medication discount programs and insurance. From a patient with CKD stage 5,

> [. . .] if I can't get the medication, diet and exercise alone aren't going to do it, at least I don't think they are going to do it. We need some stop gap measure; [. . .] I'm not saying give me the medication for free, I'm saying give to me at the discounted rate that you're giving it to me [already].

One support person recommended working at a legislative level to shift policy to promote transplant over dialysis,

> So if, is there a way that, if transplants are cheaper than dialysis, is there a way that you can pass legislation to get it more than three years? Because it would seem like you would be offsetting the expense of dialysis which the government does pay for.

Provide more LDKT information for patients and support persons. Patients, support persons, and providers recommended more materials, print and online, and classes about LDKT. A patient with CKD stage 5 suggested, "Yeah, I mean, gear it toward your friends, and family members, something for your living donors to read or watch." Patients, support persons, and providers recommended having living donors come to classes to talk to patients and their families or friends about what it was like to donate a kidney. As one provider recommended,

> An actual person that has donated a kidney would be good. They're the ones that can share that it's not that bad. 'I had these three incisions in my back, they took out my kidney, I was in the hospital for two or three days, and I'm out, and I'm back to work in three weeks.' I think having an actual person who has gone through the experience would be a good tool to include in the education.

Provide general transplant education geared toward family and friends. Patients, support persons, and providers felt that transplant education materials and classes geared specifically toward family and friends would help support patients with CKD as well as open opportunities for potential living donors to come forward. As a support person said,

> I feel that, any classes I could take, you know, as the person who would want to help her, if there were classes I could learn more, I would be willing to sign up for any and everything. I mean, I could probably go online, and learn stuff, but some of it is too technical to explain, and I guess being visual, and trying to understand, it would need to be in English—in language I could understand.

Offer in-person classes with other online learning options. Many participants appreciated the in-person classes and the ability to talk to providers. A patient with CKD stage 3 shared,

> You can't ask questions if you're reading online, but if you have somebody immediately there, and if they have people you can talk to, who are getting ready for a transplant, or after they've gone through a transplant, that's helpful to me too, so I know what to expect.

One patient with CKD stage 3 stated,

> In the classes they always have other people like the nutritionist, the pharmacist who was way more helpful than I ever thought a pharmacist could be—the social workers, liked having all of them participate, it was really helpful.

Some patients noted difficulties attending classes due to scheduling and transportation challenges. Patients and providers recommended providing online resources such as videos or websites or webinars or offering flexible scheduling to get one-on-one education from the provider. A patient with CKD stage 3 suggested, "[. . .] possibly an online class . . . if I could do it on my own schedule, which would work."

Make educational resources available in Spanish and classes taught by bilingual educators. To overcome language barriers and difficulty accessing interpretive services, patients, support persons, and providers recommended Spanish-language resources, videos, and print materials originally created in Spanish as well as classes given by a Spanish-speaking educator. A patient with CKD stage 3 recommended, "I think the DVDs [should be in Spanish] because there are people that might not be able to read Spanish or it is more about language, so the DVD would be more appropriate because it is more visual." Even when translators are available, it was recommended for materials to be in the learner's primary language. One support person stated, "[. . .] if they gave it to us in English, we would ask one of our children to read this and that when they have free time, they can explain it to us. But if it was in Spanish, one of us could read it and realize."

Help providers give culturally sensitive education. To overcome medical mistrust and specific LDKT concerns from Hispanic patients, providers need more training in cultural sensitivity for transplant education. One provider recommended, "Education for potential donors really needs to be based on the listener, and if they do come from particular ethnicities and perhaps in their cultures, they have different ideas on the body and donating, those can be addressed."

Increase support for patients post-class. Patients, support persons, and providers all agreed that it was essential to reduce the burden of learning and follow-up on patients who are overwhelmed and need additional support from their whole care team. A patient with CKD stage 5 shared, "I think there has to be a more individual understanding of what to do next, and who will be there for you. And really be cradled during that time, for a period of time." A provider stated, "But if we had better follow-up, we would probably get more people that we would start [transplant education] faster."

Discussion

In this qualitative study of interviews of patients with CKD stages 3 to 5, their support persons, and providers in Kaiser Permanente Southern California, we sought to identify barriers to kidney transplant and preferences and recommendations to optimize the effectiveness of transplant education in a coordinated care system. Common barriers to learning more about transplant included confusion about CKD diagnosis and when transplant may be necessary, concerns about the risks of transplantation, including surgery, donor safety and outcomes, and graft rejection, lack of family transplant knowledge, fears about possible financial burdens, transportation and scheduling challenges, and the emotional overload of having to learn about transplant while under the stress of managing dialysis and daily life. Hispanic- and Spanish-speaking patients specifically faced language and cultural barriers such as understanding interpreters or materials, not in their language.

The transplant community continues to debate the best time to initiate transplant education with patients in different CKD stages.[2,10-13] Nephrologists often report that patients with CKD stages 3 to 4 are not interested in learning about transplant[16] because they are overwhelmed and confused about their general CKD diagnosis. Interestingly, we found that the educational preferences of patients with CKD stages 3 to 4 differ from the recommendations of providers, as previously reported.[16] Our findings show that patients with CKD stages 3 to 4 are interested in information about managing their CKD diagnosis and avoiding transplantation and also want information about transplant wait-listing if and when their kidneys fail. Previous studies and recommendations support this, finding that patients prefer more time to learn about the transplant, find a living donor, and complete evaluation to be wait-listed.[17-19] Late referral may force patients to begin dialysis without a preemptive transplant option.[14,20,21] Recommendations on incorporating transplant education more effectively and earlier include providing general CKD education, an early introduction to transplant, specific information about how to get wait-listed and LDKT, and opportunities to hear firsthand stories from living donors and kidney recipients, which is also supported by previous research.[17,22] The respondents wanted LDKT classes and online resources for both patients with CKD and potential donors with flexible scheduling options as well as referrals to resources outside the class, such as DVDs, online videos, and print materials.

Spanish-speaking and Hispanic patients and support persons reported educational challenges due to language and cultural barriers. They recommended using bilingual educators and print, video, and online resources in both Spanish and English, and more culturally sensitive education from providers to overcome unique cultural challenges and greater rates of medical mistrust. Finally, all patients were overwhelmed by their diagnosis, managing dialysis, and learning the immense amount of information to consider transplant and pursue it. Providers, patients, and support persons felt that the onus of follow-up should be placed on the provider/educator versus the patient thereby easing patient challenges.

Limitations and Future Directions

This qualitative study is exploratory by nature and did not fully clarify the exact content or resources that should be incorporated into programs. Future research should test the effectiveness of implementing modular, health literate education tailored to the patient's CKD stage, in the patient's primary language, with the ability to learn both at-home and in-person. This education design would honor patient and provider preferences for learning within a US coordinated care delivery system. Increasing access to culturally responsive transplant education classes and online resources in multiple languages, pairing content and timing to CKD stage, and increasing follow-up as CKD progresses might help more patients make informed transplant choices and pursue transplant, if interested. These programs should be studied to see whether they are able to increase preemptive transplant and LDKT. Also, the relatively small sample size made it difficult to isolate differences in educational needs and preferences by subgroups. Future qualitative research is needed to understand patterns of CKD progression and what type of education is most helpful for patients by CKD stage.

Conclusion

As one patient described, an ESRD diagnosis is "devastating," and being given a huge booklet to read is an "insult." We should "cradle" patients at this time, share their burden of learning, and support interested patients in pursuing transplant. Then the options of preemptive transplant, deceased donor kidney transplant, and LDKT will truly be available to all.

Acknowledgments

The authors thank Angel Alum, Lizeth Ambriz, and Neha Bijjala for their contributions to this study.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project received support from the NIH NCATS UCLA CTSI (grant number UL1TR001881) and from the Health Resources and Services Administration (grant number R39OT29879).

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CE Test Test ID 4000-369: **Recommendations for Systematizing Transplant Education within a Care Delivery System for Patients with Chronic Kidney Disease Stages 3-5**

Learning Objectives: 1. Recognize common barriers to patients learning about kidney transplantation. 2. Identify techniques to help patients overcome language and cultural barriers. 3. Discuss reasons why patients may choose not to pursue living donation.

1. National Consensus Conferences recommend that transplant education first begins in CKD Stage 5 when a patient reaches end-stage renal disease (ESRD).
a. True
b. False

2. All CKD Stage 3 patients preferred not to be given information about transplantation and living donation, since it was too early.
a. True
b. False

3. Patients who do not learn about transplant early enough may be unable to get a preemptive transplant.
a. True
b. False

4. Common barriers to learning about transplant reported by many patients included:
a. They don't understand that they have chronic kidney disease (CKD)
b. They aren't sure when getting a transplant might be necessary
c. They are unable to get to classes due to lack of transportation or scheduling conflicts
d. They are overwhelmed by the amount of information necessary to learn to complete transplant evaluation
e. All of the above

5. Even with interpreters, Spanish-speaking patients still had difficulties learning about transplant.
a. True
b. False

6. Common barriers to patients pursuing living donation were:
a. Not wanting to accept a kidney from children or grandchildren due to fear about potential risks
b. Not understanding who can become a living donor
c. Fears about not being able to pay for transplant medications
d. A & C
e. All of the above

7. What idea for improving educational resources to pursue living donor kidney transplant (LDKT) was NOT recommended?
a. Make more resources available publicly for potential living donors
b. Make resources available in multiple languages
c. Provide opportunities for patients to meet living donors and kidney recipients
d. Mail brochures about LDKT to family and friends

8. Which of the following is NOT a recommendation to help patients overcome language and cultural barriers?
a. Make educational resources available in multiple languages
b. Tell the patient to bring a family member or friend to translate complex medical terms
c. Develop and distribute culturally sensitive education
d. Provide a translator

9. Patients and their support persons wanted more information on the costs of transplant and immunosuppressant medications.
a. True
b. False

10. After education, the responsibility to get a transplant should lie solely on the patient.
a. True
b. False

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

1.	**2.**	**3.**	**4.**	**5.**	**6.**	**7.**	**8.**	**9.**	**10.**
☐ **True**	☐ **True**	☐ **True**	☐ **a.**	☐ **True**	☐ **a.**	☐ **a.**	☐ **a.**	☐ **True**	☐ **True**
☐ **False**	☐ **False**	☐ **False**	☐ **b.**	☐ **False**	☐ **b.**	☐ **b.**	☐ **b.**	☐ **False**	☐ **False**
			☐ **c.**		☐ **c.**	☐ **c.**	☐ **c.**		
			☐ **d.**		☐ **d.**	☐ **d.**	☐ **d.**		
			☐ **e.**		☐ **e.**				

Test ID: 4000-369 Form expires: June 1, 2021 Contact hours: 1.0 ABTC CEPTC Fee: NATCO members, $0; Nonmembers, $35 Passing score; 7 correct (70%)

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Program evaluation

	Yes	No
Objective 1 was met	☐	☐
Objective 2 was met	☐	☐
Objective 3 was met	☐	☐
Content was relevant to my practice	☐	☐
My expectations were met	☐	☐

The level of difficulty of this test was:
☐ easy ☐ medium ☐ difficult

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If applicable: State(s) of licensure ______________________
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