Kidney Medicine

"You Gotta Keep Climbing That Mountain to Reach the Goal": Perspectives of Transplant Waitlisted Dialysis Patients. A Qualitative Study

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Rationale & Objective: There is a critical need for interventions that help improve outcomes for individuals requiring a kidney transplant but are waitlisted as inactive. We explored the perspectives of dialysis patients and clinicians to develop community aging in place-advancing better living for elders (CAPABLE)–transplant. CAPABLE utilizes a home-visiting registered nurse, occupational therapist, and handy worker who work with older adults to create action plans that change behaviors to improve safety, independence, and health.

Study Design: Qualitative semi-structured interviews.

Setting & Participants: Individuals treated with dialysis and inactive on the transplant list (n = 20) and transplant clinicians (n = 6) from an urban transplant center.

Outcomes: The adaptation of CAPABLE into CAPABLE-transplant.

Analytical Approach: Following Braun and Clark's method of thematic analysis to inform intervention adaptation.

Results: Three major themes were identified: (1) mismatch of expectations with subthemes: communication keeps breaking down; high volume at center impedes follow-up; (2) agency: from fragmentation to functionality with subthemes: patient agency needs enhancing; digital literacy is key to improving communication capacity; preposttransplant education needs to be ongoing; (3) "You gotta keep climbing that mountain 'till you reach the goal" with a subtheme of navigating compliance while struggling with symptom burden.

Limitations: A single-center perspective and small sample size.

Conclusions: By comparing the patient and clinician experience, specific adaptations for CAPABLE-transplant that address modifiable factors to decrease time inactive on the kidney transplant waitlist were identified. These included adding a digital literacy component to the home-visiting team to improve patient-clinician communication, ongoing education about the transplant process to improve health literacy, and activities to strengthen mental fortitude, self-efficacy, and agency. The core components of CAPABLE remain important to improve physical function, medication management, pain, and depressive symptoms. Patients and clinicians expressed support for CAPABLE-transplant to help improve self-efficacy, agency, and engagement along the transplant continuum.

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Kidney failure affects over 800,000 Americans, with kidney transplant (KT) being the preferred treatment. However, 47% of the 90,000 people awaiting KT in 2023 were waitlisted as inactive (not currently eligible to receive a KT), consequently facing a 2.2-fold increased risk of mortality and lower rates of transplantation.[1] There are many reasons someone with kidney failure is waitlisted as inactive including: medical conditions, physical function, incomplete testing, lack of support and/or financial constraints.[1] Black and Hispanic individuals, females, older adults and those with higher body mass index are more likely to change from active waitlist status (meaning able to receive a KT at any time) to inactive waitlist status and are more likely to remain classified as inactive longer.[2] Kidney failure is best treated with KT as this increases life expectancy, functional ability and quality of life.[3]

Further, there are stark health disparities in patients awaiting KT.[4,5] The National Kidney Foundation has prioritized improving waitlist management and transplant readiness while promoting greater equity.[6] Efforts have included passing the Organ Procurement and Transplantation Network Act, expanding patient mentorship programs, and launching self-paced online learning modules to educate people with kidney disease.[6] However low income and certain racial and ethnic groups, such as older African Americans, may use the internet less frequently.[7-9] Encouraging the use of information and communication technologies may help reduce some barriers to transplant for this community by allowing them to access online modules, mentors and other support groups.[10]

Furthering this are disparities in frailty as approximately 1 out of 6 patients on the waitlist for a KT have frailty.[11] Frailty is a multifactorial, age-related condition characterized by declines in physical, cognitive, physiological, and immune reserves, leading to reduced resilience to stressors and is associated with increased mortality, morbidity, and functional impairments.[11] Regardless of frailty patients with kidney failure struggle with high symptom burden which is also associated with higher rates of mortality, and medication, diet and treatment nonadherence, poor quality of life

PLAIN-LANGUAGE SUMMARY

People listed as inactive on the kidney transplant waitlist need interventions to decrease time listed as inactive. Qualitative interviews with dialysis patients and transplant clinicians identified areas of need that could be addressed by a home-based intervention. We used the data to adapt an existing intervention called community aging in place-advancing better living for elders (CAPABLE) into CAPABLE-transplant. Adding a digital literacy specialist to help improve patient/clinician communication; ongoing education about the transplant process to improve health literacy, and activities to strengthen mental fortitude and self-efficacy could decrease inactive time. The original components of CAPABLE—a registered nurse, occupational therapist, and handy worker to increase physical function, medication, pain, and depression management remains crucial.

and increased hospitalizations.[12] Thus, there is urgent need to further understand the barriers to KT and create interventions that target those at-risk individuals to lessen the barriers and potentially improve patient outcomes.

To address this, we are developing a novel model of care that targets barriers to active status and decrease time inactive on the KT waitlist. It is based on community aging in place-advancing better living for elders (CAPABLE). This evidence-based intervention integrates services from an occupational therapist, registered nurse, and handy worker who work with the older adult to create action plans to change behaviors that improve safety, independence and health.[13] It helps functionally limited, low-income older adults successfully age in their homes with better function, improved quality of life, with savings to Medicare of ∼$20,000 per person over 2 years.[14] CAPABLE has been tested with patients treated with in-center hemodialysis ($n = 12$) showing meaningful improvements in function and social network scores.[15] However, it has not been applied to the KT waitlist populations. By adapting CAPABLE as a KT prehabilitation program, we aim to achieve 2 objectives: (1) to address barriers preventing patients from being classified as active on the KT waitlist and (2) to serve as a holistic surgical prehabilitation intervention to improve symptom burden, agency, and quality of life.

To inform the adaptation of CAPABLE into CAPABLE-transplant we first conducted a photovoice project with prefrail or frail hemodialysis patients exploring their lived experience of their home environment.[16] Results supported the core components of CABABLE as being useful by providing in home support for dialysis patients waitlisted for a KT.[16] A brief overview of the photovoice study and examples of how the original components of CAPABLE were identified by study participants as being useful for the inactive waitlist are in Table S1.

Although we learned about symptom burden (fatigue, depression, and pain), home safety, medication management, and adaptive coping, there were specific areas involved in the transplant journey that needed further exploration to inform the development of CABABLE-transplant. This study describes qualitative interviews with patients waitlisted as inactive and clinicians that work in transplant centers in an effort to identify how we could successfully expand CAPABLE to meet the needs of those waitlisted as inactive. CAPABLE-transplant will be pilot tested in a randomized control trial.

METHODS

Study Design

A qualitative descriptive approach using human-centered design (HCD) principals was used. HCD engages potential end users of an intervention throughout the research process to tailor the intervention to the specific needs, behaviors, and preferences of the end user.[17] Within the HCD framework this study is guided by social cognitive theory. Here, human functioning is understood as a dynamic interaction between personal, behavioral, and environmental factors.[18] Social cognitive theory centers on self-efficacy, which greatly influences motivational and behavioral skills needed to wait, successfully obtain, and then live with a KT.[19,20] This approach rests on our expectation that through interviews we will be able to develop a measurable intervention informed by the needs and perspectives of adults in need of a KT who are struggling to remain active on the waitlist and the clinicians who work with them.

The semi-structured interview guides were informed by data gathered from our photovoice project.[16] Topics for patients included portal and internet literacy, nutritional understanding, and communication with transplant service clinicians. Because the KT listing process is complicated, we felt it important to gain the perspective of clinicians who work with individuals on the KT journey. Although physicians are central to decisions made about waitlist status, we were more interested in the process of coordinating patients waitlisted as inactive. Therefore, we targeted clinicians who coordinate active and inactive patients. Gaining their expertise as a complement to the patient experience provided more information to adapt CAPABLE-transplant so that it might more successfully integrate with existing services. Questions exploring clinician perspectives included the process of inactivation, reactivation, and barriers and facilitators in that process. Findings were analyzed together to compare and contrast patient and clinician experience. The interview guides are in Table S2.

Setting and Participants

Individuals were recruited who are currently awaiting KT from a transplant center where, as of June 2022, there were 1,182 participants on the KT waitlist, 510 with inactive status (43%), and an estimated 307 meeting our inclusion criteria (inactive status and 50 years or older). People who had been inactive on the waitlist for less than 5 years were prioritized as per direction from the transplant team because they have the highest likelihood of successfully transitioning to active status for transplant. Of the (n = 166) individuals we contacted, (n = 20) followed through to the interviews. Fig 1 outlines the recruitment process. Exclusion criteria were severe cognitive impairment, only being on the living donor transplant, or delisted. Recruitment stopped when an interim analysis indicated that no new information was being gathered. Participant demographics are in Table 1.

The second study population was transplant clinicians (n = 6). Nine clinicians were contacted via secure e-mails. Six clinicians followed through with an interview. Three were nurse pretransplant waitlist coordinators, one a pretransplant nurse educator, one a nurse manager of an outpatient kidney and pancreas transplant department, and one a transplant social worker. Demographic data was not collected on clinicians. (Fig 1)

Ethics

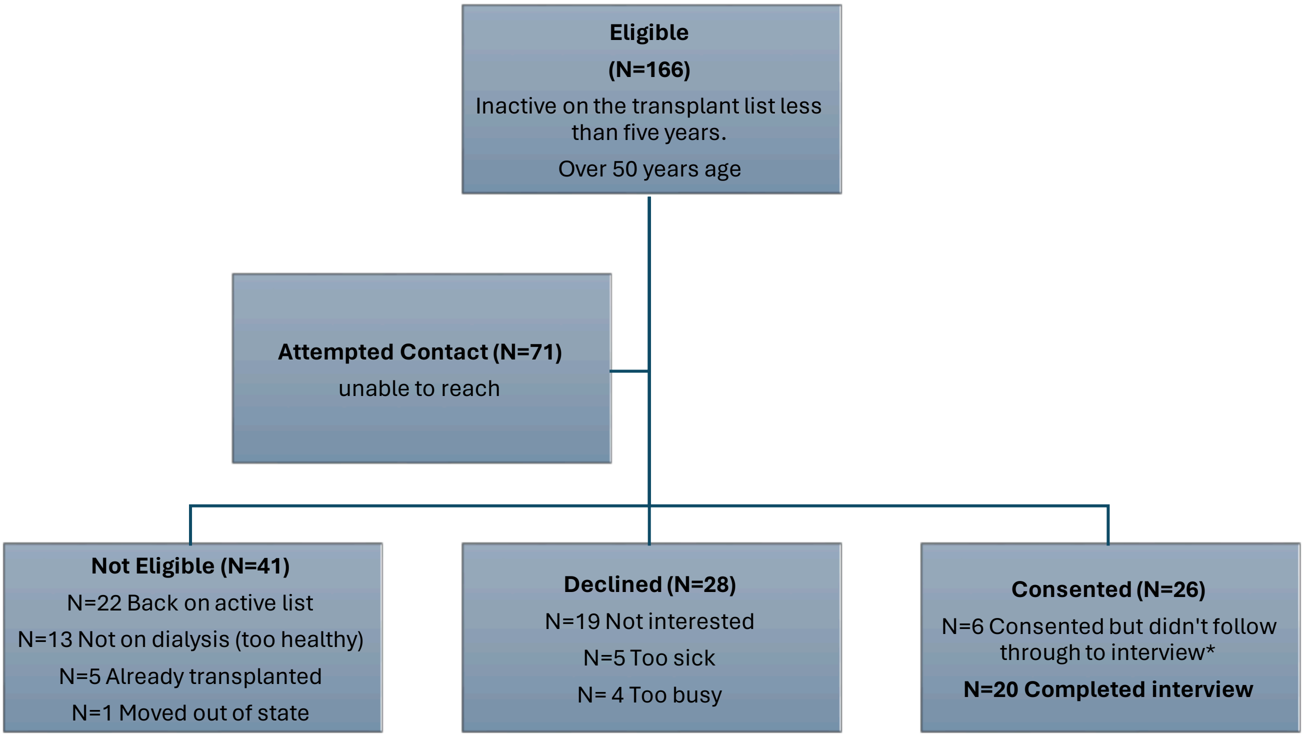
This research study was approved by the Johns Hopkins institutional review board (IRB#00298781). Oral consent was obtained over the phone or video conference platform. Consent included permission to record interviews and have findings shared in publications, and conferences. KT waitlist participants were compensated with a $50 gift card and clinicians with a $25 gift card.

Analytical Approach

Interviews were conducted via telephone by the lead principal investigator a PhD-prepared and actively practicing family nurse practitioner whose research expertise focuses on the biological underpinnings of aging, self-efficacy and resilience, and adaptation of person-environment patient-directed interventions to improve kidney disease-related outcomes. Transcription was done using Otter.ai. an artificial intelligence meeting assistant that can transcribe audio recordings (https://otter.ai/). As not as accurate as a transcription service, one research team member listened to each interview and edited transcript inaccuracies before they were uploaded into the qualitative software NVivo.[21]

The research team are trained in the use of NVivo software and using Braun and Clarkes method of reflexive thematic analysis and coding.[22] First 3 interviews were randomly chosen, and each team member coded these using an a-priori code book based on the interview questions. We then met to discuss and refine the codes. Two researchers then continued coding, meeting regularly to discuss findings and develop codes into themes that reflected areas of need for patients inactive on the KT waitlist.

Analysis began as deductive with codes based on our prior knowledge of the KT process and specific areas that



*Following consent reasons for no follow through to interview: illness, hospitalization, too busy or unable to reach at scheduled time

Figure 1. Recruitment process.

Table 1. Participant Demographics

Baseline Characteristic	n=20	%
Mean age	64 y	
Gender		
Female	11	55
Male	9	45
Race		
Black	12	60
White	8	40
Ethnicity		
Non-Hispanic/Latino	20	100
Type of dialysis		
Hemodialysis	11	55
Peritoneal	6	30
Not treated with dialysis	3	15
Reason on waitlist for inactivity		
Workup incomplete	8	40
No reason listed	7	35
No support	1	5
Back on active list	2	10
Weight	2	10

we wanted to explore with patients and clinicians. Meetings with the principal investigator who conducted the interviews further refined themes based on her experiences and observations interacting with participants during the interview process.

The lead coder was a PhD nurse with qualitative coding expertise, more specifically with indigenous and marginalized populations, but less experience with the dialysis/KT population. The second coder was a DNP nurse whose expertise centered on the clinical processes that could enable more efficient communication/connections between clinicians and KT waitlist patients. This differing expertise allowed a reflexive exploration of the emerging themes as opinions and biases were explored. Finally, the lead coder went back to the data after a few months, reading all transcripts line by line with no a-priori codes to explore for any emerging themes. This resulted in the in vivo code "You gotta keep climbing that mountain until you reach the goal." In Vivo codes are themes that utilize language used by the participant rather than being researcher derived.[22]

In the fall of 2023 and spring of 2024 preliminary findings were shared in 2 focus groups conducted with KT-waitlist patients (both active and inactive) who were supportive of the conclusions. One focus group with clinicians was conducted in the spring of 2024, who also supported the preliminary findings. See Table S3 for COREQ guidelines.

RESULTS

Three main themes emerged: mismatch of expectations, agency (from fragmentation to functionality), and "You gotta keep climbing that mountain until you reach the goal." Each of these themes influence the other. Fig 2 is a Venn diagram that depicts CAPABLE-transplant's potential to align expectations, enhance agency, and support symptom burden to enable reactivation on the transplant waitlist. Supporting quotes for each theme are in Table 2.

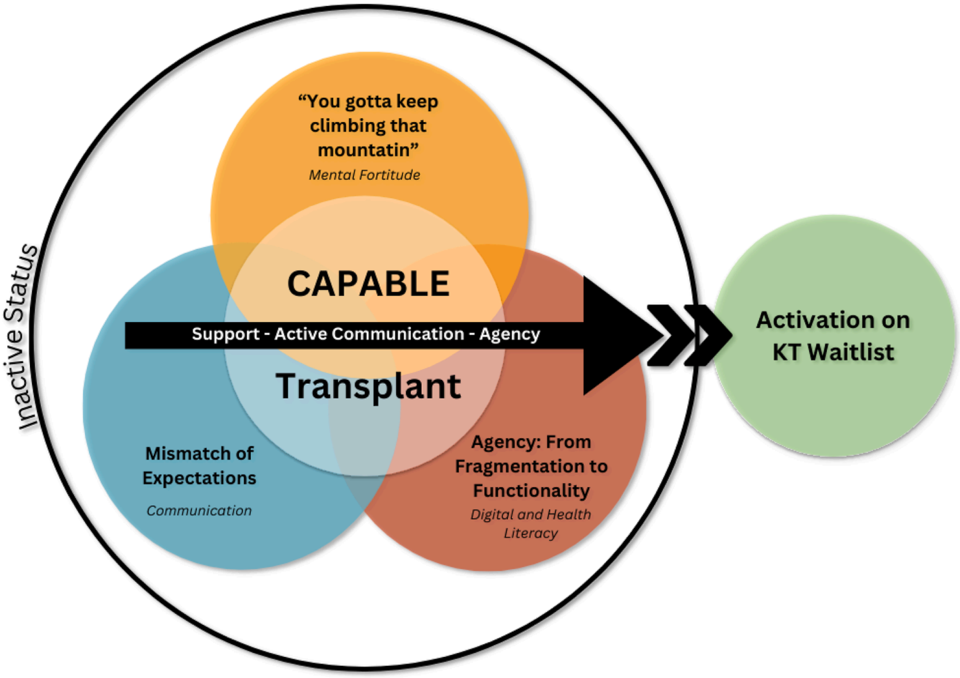


Figure 2. Interplay of the themes

Table 2. Representative Quotes for Themes and Subthemes

Theme/Subtheme	Patient Quote	Clinician Quote
Theme 1: mismatch of expectations Clinicians expect patients to maintain active communication while patients expect clinicians to be reaching out more.	".. makes me feel like I am doing this alone." CTP080	"A patient has to reach out to their transplant coordinator.and make sure that those tests get to the coordinator." CTC043
1.1. Communication keeps breaking down	"At this point I really don't know where I stand on the wait list. Am I active, what do I have to do to get active, How long will it be before I become active?" CTP077	"If we reached out three times to contact you or to get you scheduled for these things three times, we will then send a no contact letter. And if they do not follow up, then they are presented to the patient selection committee for removal [from the wait list]" CTC047
1.2 High volume at center impedes follow-up	"It would probably be helpful to have a person that contact[us] on a regular basis. And have them checking on you to make sure you're progressing some way or not, encouraging you to take more active steps. Something just so you're not forgotten." CTP078.	"It's just there's so many patients on the list and then there's always new patients that you're getting to. So, it's really hard to go back and do that [follow up with inactive patients]." CTC046
Theme 2: agency: from fragmentation to functionality Exploring the data to find out why such a mismatch in communication. Finding that digital and health literacy could increase patient agency. Clinicians need to see patients being proactive and capable of following through on requirements.	"It's the contact, that someone gets in touch with you and says, hey, hi, how are you doing? And keeps you abreast to the fact that hey, you're on the inactive list now, and that I don't find out indirectly." CTP077	"I do feel something does need to be in place because it's like these patients just, I won't say falling through the cracks but you know once they are on the list (inactive) we just kind of leave it up to the patient you know." CTC042
2.1 Patient agency needs enhancing	"Somebody's got to learn that you got to stay in touch with your people. …And you guys have never learned that." CTP077	"Patients are responsible for telling us when they've had surgery and they've had a new change in their health, if they've had insurance changes, if they're put on an antibiotic. They've been told when they need to contact us several times. It still doesn't happen." CTC047
2.2: Digital literacy: key to improving communication capacity	"I don't use it [MyChart] very often. I haven't used it in quite some time." CTP070	"I think 100% of those on top of our waitlist are on MyChart and they actively use it." CTC40
2.3. Pre-posttransplant education needs to be ongoing	"So somebody really needs to explain that [kidney transplant journey and its consequences] to people at first, when we get home, or whatever. We don't know what procedures are taken. Like I got my Medicare you know, I thought they'd cover everything. Nobody said you'll be paying out your pocket. Which I can't do because I don't have a job anymore." CTP083	"You know, it's just being educated about the process, what does it mean to be inactive? And how is that affecting me? And why is it important for me to be active? What do I need to do? I think, like more education to help patients in the long run, just improve their outcomes posttransplant." CTC040
Theme 3: "You gotta keep climbing that mountain to reach the goal" Despite not being asked about symptoms every patient described struggles with fatigue, depression, and insufficient time to manage all required tasks	**Insufficient time** "Biggest roadblock for me is not anything I can change its the dialysis time every night. It really limits your evening activities and your morning activities." CPT073. **Depression** "…Just help us to understand what is going on. Nobody told me that my feelings would be changing constantly, and I didn't know that I would be having good days, bad days. Some days I am Okay and the next day, I'm like doom and gloom. It's just an emotional roller coaster." CTP080 **Fatigue** "Working out is hard because I am tired all the time. There are some days I can't make it up the stairs. It's a struggle to get up the stairs." CTP070	"So, I'm making you inactive in June by December, I want to see perfect compliance on XY and Z. Maybe it's because your cardiac testing doesn't look good. Okay, in three months, we're going to repeat your echocardiogram, if that looks good, we can activate you…" CTC043

(Continued)

Table 2 (Cont'd). Representative Quotes for Themes and Subthemes

Theme/Subtheme	Patient Quote	Clinician Quote
3.1: Navigating compliance while struggling with symptom burden	"What I really hate… is there's no credit for weight loss from going from 330 down to 257[lbs]. And that's just not good enough. Yeah, and that kind of irritates me at times. It's like I've lost 60 something pounds. But we're quivering at 10 is the point." CTP070	"Weight loss a good measure of compliance."CTC040.

Abbreviations: CTP, center transplant patient; CTC, center transplant clinician.

Theme One: Mismatch of Expectations

A mismatch of expectations around communication emerged as the biggest roadblock. For patients, it was a lack of perceived communication with the transplant team and a belief that it was up to the transplant team to be contacting them. Communication issues ranged from not knowing that they were inactive on the waitlist to feeling they were persona nongratia because they were not active. Clinicians expressed the need to see patients be proactive and demonstrate that they are capable of managing all that is needed to be successful on the transplant continuum.

Communication Keeps Breaking Down

Despite systems processes that communicate any change in status to patients, including the steps required to become reactivated, patients commented that they did not know where they stood. Three patients (n = 3) stated that they did not even know they were inactive until contacted by us for an interview. Clinicians expressed frustration about their attempts to communicate with patients about becoming inactive and getting no response.

High Volume at Center Impedes Follow-Up

For clinicians the sheer volume of patients meant that only those at the top of the list really get the attention they need, preventing them from engaging with the inactive list as much as they would like. Conversely patients expressed a need to hear more from the transplant team to help support their progress.

Theme Two: Agency: From Fragmentation to Functionality

Because communication breakdown was discussed by both patients and clinicians, we looked through the data to identify areas where CAPABLE-transplant could support improved communication between patients and their transplant team.

Patient Agency Needs Enhancing

With increasing workloads, clinicians need patients to be their own advocate. Further, unless inactive patients are proactive about communicating with their coordinators they risk missing follow-up. One clinician acknowledged that it is really only when an inactive patient calls that they start looking into their case.

Digital Literacy: Key to Improving Communication Capacity

Although we could not identify why patients were not receiving the notification letters or transplant center telephone calls, we did notice an interesting connection to digital literacy. One clinician observed: "I think 100% of those on top of our waitlist are on MyChart and they actively use it". center transplant clinician40. Thus it stood out when participants described minimal use of the portal: "I don't use it [MyChart] very often. I haven't used it in quite some time". center transplant patient070

So we explored patients' comfort and literacy around navigating internet technology and the portal system. Few participants used the internet to educate themselves about their condition and find options describing 'relying more on their doctors for information.'

Pretransplant and Posttransplant Education Needs to be Ongoing

Clinicians identified health literacy as an issue for some on the inactive list. "So, patients who are reactivated on the transplant list typically have a higher health literacy." center transplant clinician040. They also acknowledged that there is an overwhelming amount of information that a patient must process. Patients acknowledged that keeping abreast of all the information needed to be successful on the transplant continuum was overwhelming.

Theme Three: "You gotta keep climbing that mountain to reach the goal"

As we had explored symptom burden in the photovoice study[16] we did not specifically ask about this in these interviews. Despite this, patient participants described symptom burden as a barrier to managing the requirements outlined by the transplant team. The most frequent barriers discussed were insufficient time, depression, and fatigue.

Navigating Compliance While Struggling With Symptom Burden

Navigating required medical tests and benchmarks that must be met to stay on the KT waitlist eg, body mass index, and the 6-minute walking test, while struggling with symptom burden and attending/completing dialysis requires mental fortitude and self-efficacy. Despite supportive family, a strong faith, and even a positive attitude many participants expressed that professional support in the home would help them more successfully navigate the transplant journey. All clinicians expressed the importance of compliance as one measure they use of success posttransplant.

DISCUSSION

The purpose of this study was to explore both patient and clinician perspectives on the needs of those on the inactive KT waitlist to inform adaptations of CAPABLE to CABABLE-transplant. There is limited published literature on the inactive patient's specific barriers to staying active on the waitlist.[23] To our knowledge there are no randomized controlled trial studies addressing barriers to KT waitlist activation nor any programs that address patient-directed goals and the home environment among those inactive awaiting KT, making it important that these areas be explored. Based on findings from this qualitative study extensions to the CAPABLE program include enhancing communication capacity and implementing supports to manage symptom burden and promote agency. This CAPABLE-transplant adaptation has the potential to positively influence KT-related waitlist disparities.

Effective communication between nurse-patient and physician-patient has been shown to be an indicator of adherence to treatment.[24] By incorporating a digital access specialist into the CAPABPLE-transplant home-visiting team, patients' knowledge and skilful use of the internet and portal access (eg, MyChart) could be enhanced. This would support patient agency, reducing the sense of fragmented care and the risk of patients falling through the cracks.

Further, analysis revealed a gap in patients utilizing the internet for knowledge acquisition and social support (such as KT Facebook groups). CAPABLE-transplant's digital access specialist and nurse could educate clients on utilizing online support groups, webinars, and trainings to increase understanding of the inactive/waitlist process. By increasing digital and health literacy, we hope to promote effective communication. This can increase motivation to improve one's state of health and adherence to treatment.[25,26] It may help address data showing that older African Americans and those of low socio-economic status are additionally disadvantaged because of the lack of access, or use of internet resources.[8]

Other ideas to support improved communication include a goal board that outlines plans to complete required pretransplant workups, lists the name and telephone number of their transplant coordinator, and inspiring/motivational quotes. By intervening in the home, providing education, and having these discussions in a safe environment, older adults may also be more proactive about moving forward on the transplant continuum.

The frailty and symptom burden that these patients struggle with indicate that the original components of CAPABLE will also be useful for this population—the handy worker, registered nurse and occupational therapist to work on person-environment fit in the home, medication management, and increasing physical function, for example. This could help improve a patient's agency and autonomous ability to complete required tasks. Evidence suggests that higher self-efficacy and agency can lead to the ability to successfully take on challenges and responsibilities.[27]

Weight management is a modifiable factor that can enable a participant to move to the active waitlist. CAPABLE-transplant can help assess nutritional understanding, and support home-based exercise programs. Promoting and supporting physical activity and evaluating nutritional needs helps manage comorbidities, blood pressure, improves mood and health-related quality of life for patients waiting for a KT.[28] It may help reduce the risk of waitlist mortality, a concern for frail older adults who are inactive on the KT wait list.[29,30] This dovetails into the need we identified for CAPABLE-transplant to support mental fortitude. Symptom burden is associated with depression, greater risk of hospitalization, and lower quality of life.[31,32] Although participants described existing support mechanisms this study identified a need to incorporate ways to improve mental fortitude and resilience. This can help enhance adherence to treatments and be protective against depression.[33,34]

Although workload volume was an issue for clinicians, they expressed concerns that patients on the inactive list were at risk of being inadvertently ignored, yet it is important for clinicians to see these patients following through on required testing, medication management, and attending appointments. Early nonadherence to laboratory and clinic appointments is a strong predictor of late medication nonadherence, acute rejection, and graft loss posttransplant.[35] Thus, by providing support in the home, improving communication capacity, and increasing health literacy, CAPABLE-transplant could strengthen adherence, which would indicate to transplant coordinators that such compliance could continue posttransplant. This may address the tension that transplant centers are under to ensure that the limited supply of organs is given to people who will most likely succeed posttransplant.

Although processes are in place to notify individuals that they have been made inactive with instructions on what is required to return to the active list, we again saw a gap. Clinicians have worked out personal systems to remind them of required follow-ups but acknowledged that these are not perfect. While out of scope for CAPABLE-transplant there is a need to improve the process of reviewing inactive patients on the waitlist by clinicians/transplant centers. The potential of transplant coordinators comparing systems nationally and working together would be an interesting area of research and development in the future. Recent research has demonstrated that efficient health IT implementation does improve nurse-patient communication and patient outcomes, as nurses are critical to the flow of information between a center and patient.[24]

This study has limitations. First, there is ascertainment bias. We assessed a community of people who are sick, and the effort required to sign up and participate in an interview limits the number of people we were able to recruit. Thus, of the (n = 166) patients we initially contacted only (n = 20) completed the interview process. Our conclusions are based on a single-center perspective and cannot be generalized to all centers nationwide. Further this study is qualitative, and thus the information gathered is based on personal experience and perspective, not quantitative data.

Researcher bias cannot be ruled out. By discussing our reactions to the data and having a diverse team of coders with different experiences of the transplant continuum, we hope that this has been minimized. Further, our goal was largely focused on finding areas in which the adaptation of CAPABLE could be effective; thus, there may be themes that were missed. However, by using HCD principles we prioritized end-user perspectives to inform the development of a community-based/home-environment-focused intervention.

Finally, CAPABLE-transplant has the potential to empower patients and their support groups to engage more in the transplant journey; thus, supporting organ transplant affinity group initiatives.[36] As patient adherence to prescribed medications, appointments, and testing is a predictor of posttransplant medication adherence and success[35] an intervention that promotes agency could potentially enhance the possibility of transition back to the active waitlist and readiness for transplant. Patients more actively engaged may also help provide data that supports centers as they transition to the increasing organ transplant access model.[37]

In conclusion the data gathered in this qualitative study has been able to inform the adaptation of CAPABLE into CAPABLE-transplant a home-based intervention that could support and motivate individuals listed as inactive on the KT waitlist to become reactivated and ultimately successfully receive a kidney transplant.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Table S1: Overview of Photovoice Study

Table S2: Semi-structured Interview Guides

Table S3: COREQ Guidelines

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