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REVIEW ARTICLE

Expanding the access to kidney transplantation: Strategies for kidney transplant programs

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Abstract

Kidney transplantation is the most successful kidney replacement therapy available, resulting in improved recipient survival and societal cost savings. Yet, nearly 70 years after the first successful kidney transplant, there are still numerous barriers and untapped opportunities that constrain the access to transplant. The literature describing these barriers is extensive, but the practices and processes to solve them are less clear. Solutions must be multidisciplinary and be the product of strong partnerships among patients, their networks, health care providers, and transplant programs. Transparency in the referral, evaluation, and listing process as well as organ selection are paramount to build such partnerships. Providing early culturally congruent and patient-centered education as well as maximizing the use of local resources to

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facilitate the transplant work up should be prioritized. Every opportunity to facilitate pre-emptive kidney transplantation and living donation must be taken. Promoting the use of telemedicine and kidney paired donation as standards of care can positively impact the work up completion and maximize the chances of a living donor kidney transplant.

KEYWORDS
access, access to health care, barriers, health equity, kidney, kidney transplantation, transplant recipients

1 | INTRODUCTION

Kidney transplantation (KT) is the optimal treatment for end stage kidney disease (ESKD), providing improved survival, quality of life, and substantial cost savings compared to dialysis.[1] Although kidney transplant rates have been increasing, in 2018, the actual rate among patients receiving dialysis was only 3.6 per 100 person-years.[2] A growing body of literature has identified several multilevel barriers and disparities in access to kidney transplantation at a patient, provider, and health systems level. In 2022, the American Society of Transplantation (AST) Kidney Pancreas Community of Practice (KPCOP) formed the Access Workgroup to identify opportunities and strategies that help overcome key barriers limiting kidney transplantation. The workgroup met over several months and reviewed the available literature with the goal of summarizing the various barriers to kidney transplantation and focusing on key areas of the transplant process (pre-emptive transplantation, evaluation, waitlisting, organ utilization, re-transplantation, and living donation) where interventions can be most impactful in maximizing access to kidney transplantation. In this manuscript, we present our key recommendations.

2 | BARRIERS AND OPPORTUNITIES AT THE PROVIDER AND TRANSPLANT PROGRAM LEVEL (TABLE 1)

2.1 | Maximizing the odds of a preemptive kidney transplantation

Pre-emptive kidney transplantation (Pre-KT) (i.e., transplantation prior to requiring dialysis), particularly from a living donor (LD), confers superior patient and allograft survival, and improved quality of life.[3,4] Nonetheless, only 9%–11% of deceased donor (DD) transplants and 39% of LD transplants in 2000–2018 were pre-emptive. Pre-KT recipients are more likely to be White, older, female, have higher education, and private insurance.[5] Compared to White patients, black patients have 37% lower odds of pre-emptive referral after adjustments for clinical, socioeconomic, and neighborhood factors.[6] In 2022, the National Academies of Sciences, Engineering and Medicine (NASEM) released a report with recommendations to improve fairness, equity, transparency, and cost-effectiveness in organ transplantation. NASEM recommended eliminating pre-dialysis waiting time points from the kidney allocation system (KAS) to reduce racial and ethnic disparities. Though well intended, such recommendation can negatively impact posttransplant outcomes by reducing the morbidity and mortality benefit that comes with pre-emptive waitlisting and transplantation.[7]

Delayed referral to nephrology and, subsequently transplant centers, results in underuse of Pre-KT. One in three patients starting dialysis in the U.S. had no pre-ESKD nephrology care.[8] Patients referred to a nephrologist within 3 months of ESKD, rarely receive a transplant, contrasting with those referred at an estimated glomerular filtration rate (eGFR) of ≥20 mL/min who have a greater likelihood of obtaining a Pre-KT.[9]

Timely referral and early KT education are key elements to promote Pre-KT. The Organ Procurement and Transplantation Network (OPTN) guidelines recommend KT and LD discussions to begin at an eGFR of 30-35 mL/min. Patient-centered, culturally targeted education, performed in partnership between transplant programs and referring nephrologists is imperative. Free and readily available multimedia platforms such as the United Network for Organ Sharing (UNOS) KT learning center should be used.[10] Implementing Patient Navigator programs early, prior to developing ESKD, and throughout the CKD continuing holds promise.[11] Likewise, partnering with communities to raise awareness an simplifying the transplant referral process can expedite waitlisting and Pre-KT.

2.2 | Enhancing the evaluation process

In its current form, the evaluation process has proven inefficient to increase the number of waitlisted patients; less than 50% of patients <40 years old are listed.[12] Waitlisting requires the completion of a complex multi-step process including meeting with various transplant team members and specialists and undergoing multiple diagnostic tests.[13] Interventions to reduce this burden are urgently needed.

Selection criteria among transplant centers vary and often, are not patient centric. These rather reflect a program's risk tolerance to certain patient attributes (e.g., higher body mass index, age, smoking status) and donor organ offers (e.g., high Kidney Donor Profile Index

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TABLE 1 Barriers and opportunities at the provider and transplant program level.

Level of action	Barriers	Opportunities
Preemptive kidney transplantation	- Low rate of pre-emptive kidney transplants o Delayed referral to transplant programs o Lack of pre-dialysis nephrology care o Incentivization of dialysis compared to transplant - Disparities in referral patterns usually affecting underrepresented minorities - Insufficient/inadequate or absence of insurance	- Timely referral to nephrology care and transplant programs - Education of primary care and general nephrology providers regarding preemptive transplant - Wider use of existing multimedia platforms and resources for referring providers to educate patients (i.e. UNOS kidney transplant learning center) - Implementation of patient navigation programs to provide patient-centered, linguistically and culturally concordant - Partnering with community advocates especially in historically disadvantaged communities - Routine use of telemedicine to augment access
Evaluation process	- Complex multi-step process - Psychosocial barriers - Insufficient/inadequate or absence of insurance - Variable selection criteria (BMI, Organ offer, high KDPI offers, acceptance of Hepatitis C+ offers)	- Promotion of transparent and publicly available selection criteria - Utilization of patient navigators and/or peer support/guidance to maximize evaluation completion - Ensurance of appropriate program staffing - Maintenance of accessible and fluent communication between transplant stake holders (i.e. patients, transplant programs, referring providers) - Consolidation of testing to the shortest time interval possible (days to weeks instead of months) - Engagement of local providers in the evaluation process
Organ utilization	- High rate of inactive status among waitlisted patients - High organ discard rate - Variable organ acceptance - OPO practice variability - Inadequate use of bypass filters	- Rigorous waitlist management - Greater transparency in organ selection practices - Shared decision making - Utilization of COIIN initiative (or similar) to improve the use of high KDPI organs. - ETCLC-Improvement of the procurement of organs with KDPI 60–85 - Thoughtful use of ABO/HLA incompatible living donors and Hep C positive organs - Balance between OPTN offer acceptance rate ratio and 90 day or 1 year graft survival
Donor-recipient incompatibility	- Racial disparities among ABO incompatibility, highly sensitized patients - Augmented risk of rejection and graft loss	- Judicious use ABO-incompatible transplantation and desensitization protocols - Enhanced use of Kidney Paired donation
Relisting and retransplant after allograft failure	- Low pre-emptive relisting and retransplantation rate - Lower rates of relisting and retransplantation in traditionally underrepresented minotities - Factors contributing to previous graft loss: nonadherence, augmented comorbidities, advancing age, and risk of recurrence of primary kidney disease - Sensitization from previous failed transplant	- low level immunosuppression balanced against risk of continuation - Prioritization preemptive kidney transplant - Consideration of transplant nephrectomy in a case-by-case basis

(KDPI) kidneys) usually in response to regulatory requirements.[14] The transplant community should promote transparency and make selection criteria at a transplant center publicly available to help patients decide where to seek transplant evaluation.[15] Likewise, continued support and assistance is helpful. In a single center randomized control trial of 401 patients,[16] those assisted by a trained navigator were 3.3 times more likely to be waitlisted after 500 days (HR 3.3, 95% CI = 1.2–9.1). Transplant programs should strive to maintaining adequate staffing to support and assist patients; the OPTN can provide comparison statistics for transplant program staffing benchmarks.

Transplant programs should simplify evaluation protocols, consolidate diagnostic testing and consultations, and offer telemedicine evaluation[17] as standard of care. In a single center study,[18] patients undergoing a one-day coordinated evaluation were three times more likely to be waitlisted (46 vs. 226 days, $p < .001$). Unnecessary or redundant testing unsupported by data, should be avoided or minimized. For instance, non-invasive coronary artery disease testing of low-risk asymptomatic patients is not recommended by Kidney Disease: Improving Global Outcomes (KDIGO) guidelines,[19] yet many transplant programs apply such testing universally despite studies failing to show a significant reduction in death or acute MI within 30 days

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of KT.[20] Standardizing workup and sharing information of tests within and between Institutions could result in time and cost savings.

2.3 | Prioritizing transparency and amplifying kidney utilization

OPTN data show that approximately 13 people die daily while waiting for a life-saving KT. The transplant community has the obligation to increase organ utilization while limiting non-placement. First, transplant programs should gain proficiency in the use of less -traditional kidneys, such as Hepatitis C donors, pediatric en-bloc, blood type non-A1 to B, donors after cardiac death, and high KDPI donors. Second, programs should aim to reduce cold ischemia time (CIT) by incorporating virtual crossmatching and clearly defining their organ acceptance patterns. However, long CIT should not be an insurmountable barrier and when possible, kidney should be placed in hypothermic mechanical perfusion.

Though the U.S. enjoys a low primary non-function rate after kidney transplant, according to the ESRD Treatment Choices Learning Collaborative (ETCLC), the rate of organ recoveries without transplantation is one of the highest at >25%.[21] Organ procurement and discard vary depending on the day of the week[22] and OPTN region. Commonly, these offers are declined on behalf of patients without shared-decision making, introduce inconsistency in transplant rates and potentially, exacerbate inequities.[23] Existing variations in organ acceptance criteria, staffing and resources within programs and regions, lead to differences in the probability of a DD KT even among programs working with the same pool of organs supply.[24] The now common automated “bypass filters” (pre-specified criteria intended to filter out organ offers that are likely to be turned down by a given transplant program) further limit a patients’ access to transplantable organs while minimally improving allocation efficiency.[25] Calls for greater transparency are happening so that bypass choices are made apparent to patients through improved communication and shared decision-making.[26]

Several initiatives have been undertaken to improve organ utilization since nearly 10% of patients with a previously declined organ offer die on the waitlist, and another 20% are removed without a transplant.[27] In 2015, the Collaborative Innovation and Improvement Network (COIIN) sought to increase the use of kidneys with a KDPI >50%.[28] Most recently, the ETCLC collaborated to increase the percentage of kidneys recovered for transplant with a KDPI of 60%–85% but the project failed to reduce the discard rates of these organs, now nearing 50%.[29] Unfortunately, these initiatives and other accelerated placement projects have fallen short of expectations.[30,31] OPOs remain under tremendous pressure to get organs placed, and thus, out of sequence placements are increasingly more common (16% of recent transplants); these do not follow a match run and may exacerbate inequities.[32,33] Transplant programs will need to find balance between the OPTN metrics of offer acceptance ratio and post-transplant ninety-day and 1-year graft survival while maximizing organ utilization.

2.4 | Identifying strategies to address immunologic barriers

HLA sensitization and ABO incompatibility pose a big challenge to transplant access. Approximately 30% of KT candidates with a LD are unable to proceed with transplant even though HLA incompatible LD transplant provides survival advantage compared to staying waitlisted.[34] Incompatible transplants primarily disadvantages racial and ethnic minorities, and women.[35,36] The emergence of kidney paired donation (KPD) has largely reduced the need for desensitization and positive cross match transplants. Yet, as KPD pools become saturated with sensitized patients,[37] identifying straightforward compatible matches has proven harder. Thus, judicious use of HLA desensitization protocols alone or complimentary to KPD (Figure 1) will need to continue in order to maximize timely and safer access to kidney transplant and despite the concerns for variable efficacy and risk of graft failure.[34,38,39]

Non-A1/A1B to B deceased donor kidney transplants remain underutilized even though it increases transplantation rates for eligible patients. Under KAS, qualifying patients experienced a 133% greater rate of transplantation. Anti-A titers of ≤16 are reported to be safe with excellent short-term outcomes[40] and no differences in the 7-year adjusted mortality or death-censored graft failure compared to B-to-B transplants.[41] However, between 2014 and 2022, only 12.6% of blood type B recipients were listed for this option. Transplant programs need to gain expertise and confidence in performing non-A1/A1B to B deceased donor kidney transplant and allow the expansion of non-A1/A1B listing for all qualifying patients.

2.5 | Relisting and re-transplantation after allograft failure

One in five patients experience allograft failure within 5-years of transplant, and more than half will experience graft loss by 10-years.[2,42] Patients with kidney allograft failure represent 4%–10% of U.S. incident dialysis patients,[43] and experience greater mortality compared to transplant naïve waitlisted patients.[44] Kidney re-transplantation carries a lower mortality risk compared to remaining on dialysis even among high risk subgroups like diabetics and the elderly.[45–47] However, pre-emptive relisting and repeat KT rates are lower than expected and disproportionally worse among racial and ethnic minorities and people of lower socio economic status (SES).[48]

Re-transplanting after a failed KT post many challenges that serve as barriers to future KT. These include sensitization, potential for nonadherence, augmented comorbidities, advancing age and a risk of recurrence of the primary kidney disease. Understanding the allograft pace of decline and prognosis can help establishing a timeline[49] to re-refer for KT, early discussion (and identification) of LD while working to prevent future allosensitization by maintaining some degree of immunosuppression, even after transplant nephrectomy.[50,51] The decision to continue immunosuppression must be balanced against the risk

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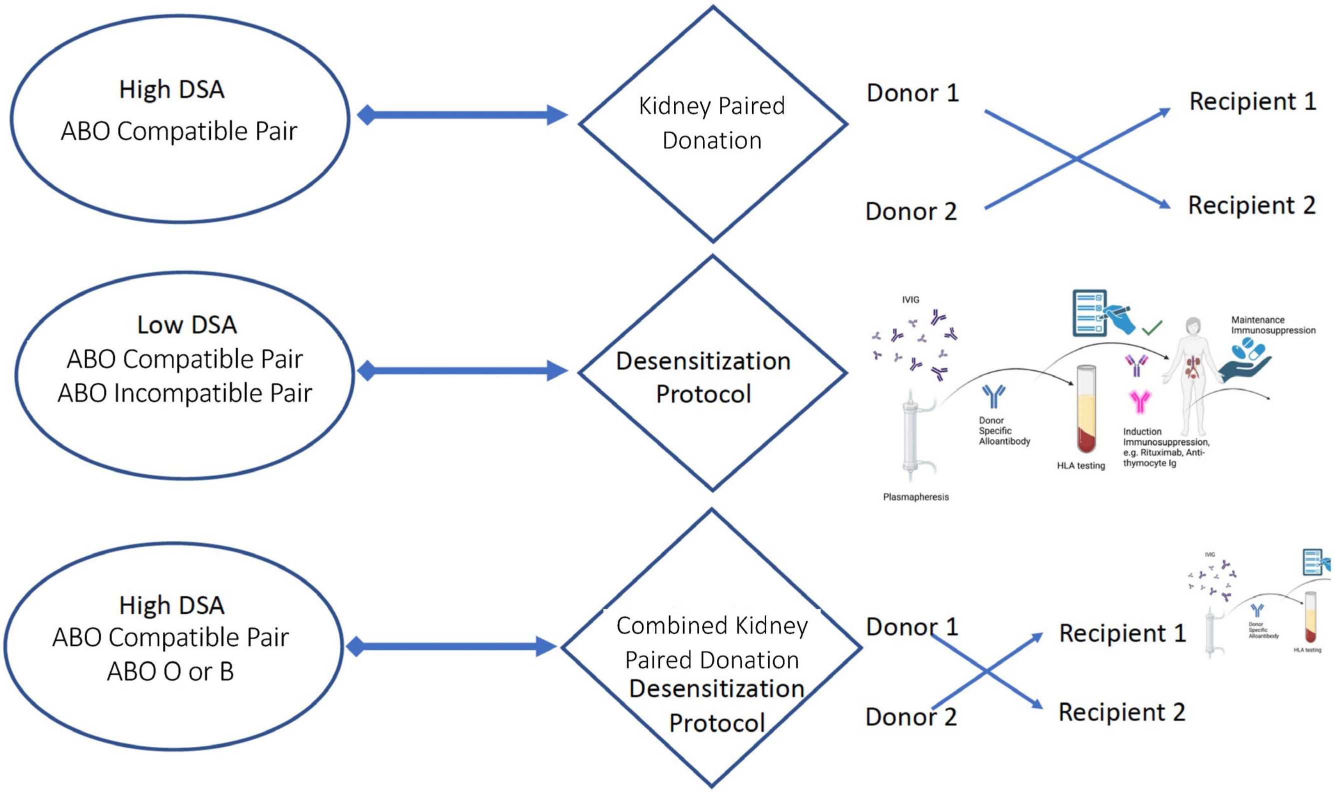

FIGURE 1 Best options for improved access to living donor kidney transplantation for ABO and HLA incompatible patients. Patients with high DSA and/or ABO incompatibility (high isoagglutinin titers) benefit from participating of kidney paired donation to identify a compatible living donor. In selected cases, these patients require concomitant use of desensitization protocols to facilitate an exchange; such approach is more efficient than desensitization alone. Patients with low DSA and/or low insoagglutinin titers driving ABO incompatibility, can be responsive to desensitization and have good graft outcomes.

of infection, malignancy, and prospects of re-transplantation.[52–55] The approach to the patient with a failing allograft must be individualized.

3 | BARRIERS AND OPPORTUNITIES AT THE PATIENT AND COMMUNITY LEVEL (TABLE 2)

3.1 | Bridging gaps through improving health literacy and cultural congruent education

The National Institutes of Health defines health literacy as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.[56] Insufficient health literacy can negatively impact all steps in the transplant process. In a single center survey, education about transplant and other treatment options given early resulted in an increased likelihood of undergoing a Pre-KT. The survey also highlighted patients' misconceptions that dialysis must precede KT, concerns regarding costs and hesitance in approaching potential LD.[57] Kucirka et al. reported that disparities in provision of transplant information also affected access to KT.[58] Grubbs et al. found that roughly a third of study participants lacked enough health literacy and that it correlated with a lower likelihood of being referred for transplant evaluation, but not of being waitlisted.[59,60] Other studies have shown an association between limited health literacy and lower likelihood of being waitlisted.[61] Thus, efforts to ensure sufficient education about the benefits of KT and LD, starting soon after the diagnosis of kidney disease, must take place.[62] The education should be multidisciplinary, multimodal (i.e., verbal, written, audiovisual) and delivered at multiple contact points.

Racial and ethnic inequities are observed throughout the transplant evaluation continuum.[63,64] To minimize potential for provider bias, culturally sensitive education tools should be used, and practices standardized. Transplant programs should consider including in their teams a patient navigator to complement the education provided and aid patients through the completion of the highly complex pre-transplant workup process. Moreover, providing culturally and language concordant care can enhance patient-provider communication and patient satisfaction.[65] The Northwestern's Hispanic Transplant Program has successfully delivered cultural and linguistic congruent care to the Hispanic/Latinx population for years. Participants of this program have demonstrated increased knowledge of transplant and living donation and positive attitudes toward living donation.[66] Their transplant center also experienced significant increases in both waitlisting and living donor kidney transplant among these population.[67] Given the

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TABLE 2 Barriers and opportunities at the patient and community level.

Level of action	Barriers	Opportunities
Education and literacy	- Poor health literacy primarily affecting underrepresented minorities - Suboptimal transplant education - Provider bias	- Early and continuous transplant education in CKD population preceding referral to transplant programs - Emphasis in preemptive transplant education and living kidney donation education - Promotion of culturally concordant and language competent multidisciplinary education
Financial and geographical challenges	- Inadequate/insufficient or absence of insurance - Distance to transplant program - Inadequate/insufficient transportation - Digital illiteracy and variable access to Telehealth options o Post-pandemic reimbursement challenges, o Practice-limiting state licensing laws o Liability concerns	- Expansion of insurance coverage (Medicaid) - Early and consistent involvement of Social Workers - Routine availability of satellite clinics within a patient's community - Expansion of Telehealth coverage o Medical license portability across state lines o Greater use of interstate medical licensing agreements
Psychiatric and substance use disorders	- Provider bias against patients with a history of mental health disorders - Inconsistent approach to and acceptance of patients with mental health disorders - Variable acceptance of patients using cannabinoids	- Recognize not all substance use are absolute contraindications - Provision of pre-transplant counseling and treatment of mental health disorders to enhance post-transplant outcomes - Clear guidance to patients about the mental health and substance use disorders that constitute contraindications to transplant
Social support and adherence	- Insufficient/inadequate or absence of care partner and transportation - Evidence of poor or inconsistent treatment adherence - Inflexible social support requirements and/or limited consideration of less standard social support - Non-behavioral systems' factors for non-adherence such as employment conflicts, childcare or dependent care and misconceptions about medications	- Recognition of the inconsistent relationship between post-transplant outcomes and the availability of social support and treatment adherence - Multidisciplinary consensus to define transplant caregiving needs, roles and responsibilities. - Recognition and mitigation of nonadherence early in the pre-transplant process
Patient population changes	- Aging population wit advanced kidney disease conflicts with patient selection criteria age cut off - Provider biases and reluctance to refer and list older patients - Growing presence of physical and cognitive frailty - Increased prevalence of obesity and greater comorbid index among CKD patients	- Implementation of pre-habilitation and physical therapy to improve physical functioning sufficiently to allow transplant - Utilization of assessment tools that adequately measure frailty to allow the implementation of interventions to facilitate transplant and improve outcomes. - Use of robotic surgery techniques, surgical weight loss programs, and medical weight management programs to adapt to population changes

success of this program, a "sister" program to address the Black ESKD community is currently underway.[68]

3.2 | Narrowing the financial and travel gaps

It is well established that race, SES, and ethnicity are associated with lower access to transplant. Even after adjusting for demographic, clinical, and SES factors, Black patients had 59% lower transplant rate than White ones.[69] Similarly, inadequate insurance coverage, more common in marginalized communities, leads to reduced referral for transplantation. Expanding insurance coverage (i.e., Medicaid) and including transplantation as an essential health benefit may help. Providing social work services throughout the CKD care continuum and into transplant could improve utilization of community resources and health benefits (i.e., transportation, medication coverage, Medicare/Medicaid plan selection).

Living farther from a transplant program correlates with a lower referral rate, completion of transplant evaluation,[70] and has a higher risk of transplant failure.[71] A survey to dialysis units and transplant center staff within the ESRD Network 6 concluded that the distance to a transplant program (29.7%) and inadequate transportation (63.7%) were the two (out of five) most important barriers to transplant. Further, the survey noted that providing transportation and financial assistance could have the greatest impact in transplant candidacy.[72] On the contrary, a study by McPherson et al., multivariable analyses showed that distance was not associated with likelihood of referral or evaluation. These analyses were adjusted for dialysis for-profit status, so this conclusion is unlikely to be confounded by this factor.[70] As such, travel gaps are not broadly generalizable.

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Regardless, every attempt should be made to minimize such barriers through implementation of satellite clinics and universal utilization of telehealth services,[73–75] provided that changes to post-pandemic reimbursement practices,[76] state limiting licensing laws and liability concerns restricting care are addressed.[77] Allowing for medical license portability across state lines and greater use of interstate medical licensing agreements could be potential solutions.[78]

3.3 | Improving transplant access for patients with psychiatric illness and substance use disorders

Preexisting untreated psychiatric illnesses are considered relative or absolute contraindications at many transplant programs.[79,80] Yet, the impact of these conditions on transplant outcomes is unclear and warrants further investigation.[81] Similar concerns exist for patients with substance abuse and tobacco dependence. Such patients are less likely to be waitlisted and transplanted[82] and may have poorer treatment adherence post-transplant.[83,84] The KDIGO 2020 guidelines recommend that candidates with a psychiatric/psychological or substance use disorder undergo pre-transplant counseling and treatment. The guidelines recommend delaying transplant if these conditions affect a patient's capacity for decision making or puts the candidate at an unacceptable level of post-transplant risk[19]

Many transplant programs consider cannabis use a partial or absolute contraindication despite no definitive evidence of direct harm.[85,86] Cannabis classification as an illegal, schedule I substance under federal law contradicts a growing state-level more permissive legislation and adds to the challenge of evaluating candidates using cannabis. Thirty-eight states, 3 territories and Washington, D.C. have legalized medical cannabis use,[87] and 11 states have anti-discriminatory law prohibiting the disqualification for transplant solely on based on medical cannabis use.[88] We suggest robust pre-transplant counseling and treatment and to refrain from considering all substance use (i.e., marijuana) absolute contraindications. A program's criteria with regards to substance use should be made available to patients.

3.4 | Balancing sufficient social support, adherence, and timely transplant

There are no best practice guidelines to assess patients' social support systems. Yet, this is done routinely[89] as it is deemed crucial to transplant success. One systematic review found an inconsistent relationship between availability of social support, treatment adherence and post-transplant outcomes.[90] A survey of 276 transplant psychosocial clinicians noted it was common (92% of participants) to decline candidates with *"insufficient"* social support despite highly variable definitions.[91] The OPTN Ethics Committee noted that inflexible social support requirements contribute to worsening disparities; candidates from vulnerable populations are less likely to fulfill stringent requirements due to greater inability to miss work, childcare costs, etc.[92] The Organ Transplant Caregiver Initiative, a multidisciplinary stakeholder group aimed at identifying transplant caregiving needs, resources, and research priorities,[93] recently developed a toolkit to help define transplant caregiver roles and responsibilities.[94]

Adherence assessment also impacts transplant candidacy. Programs frequently use attendance to dialysis to measure adherence[95]; shortening dialysis treatments (rather than missing them) has a significant association with greater risk of acute rejection.[94] However, non-behavioral factors like lack of transportation, employment conflicts, and misconceptions about the adverse effects of missed dialysis, are the most common reasons behind non-attendance[96] Posttransplant non-adherence to clinic and laboratory appointments also functions as a strong predictor of medication non-adherence and acute rejection[97] and it is negatively influenced by access to transportation, cost of travel and low socioeconomic status.[98] A number of interventions to enhance adherence in the context of transplant have been trialed. Taber et al.[99] developed a technology-enabled-pharmacist led intervention to successfully improve medication adherence and outcomes in kidney transplant. In 2023, the AST Transplant Pharmacy Community of Practice created the "Transplant recipient adherence monitoring and management tool" with the goal to provide resources to transplant professionals to optimize adherence monitoring and management after transplant. This tool is free and publicly available for transplant providers to use.[100]

3.5 | Adapting to an increasingly frail, aging, and obese candidate pool

Older age remains a barrier to KT despite 24.8% waitlisted candidates being ≥65 years old in 2020.[101] KDIGO guidelines recommend no absolute age cutoff and suggest that candidacy be assessed in the context of other comorbidities. Frailty, defined as the presence of limited physiologic reserve and resistance to stressors, is influential on a patients' candidacy and post-transplant outcomes. Once transplanted, frail KT recipients have twice the risk of dying.[102] Frailty measurements carry risk of gender discrimination, and women are significantly less likely to get referred, listed, and transplanted than men, despite evidence that frail men have a 2.6-fold higher mortality rate than frail women.[96] Objective frailty scoring systems, rather than subjective physician assessments, should be applied at the time of evaluation.[103,104] Frail candidates should be offered a targeted "prehabilitation." Research to define the best methods to assess frailty and determine the right interventions to improve posttransplant outcomes is urgently needed.[27]

Many concerns surround KT in obese candidates such as surgical complications and premature death censored graft loss.[105] Nevertheless, these patients have a clear survival benefit with KT compared to remaining on dialysis.[106,107] It is imperative to identify ways to facilitate safe transplants in this group. Transplant programs should educate and assist with referrals bariatric clinics and involve community physicians in utilizing newer weight loss therapies. Many programs are more permissive with BMI cut-offs and have incorporated innovative surgical techniques that reduce operative complications. In a single center

TABLE 3 Barriers and opportunities at the policy and system level.

Level of Action	Barriers	Opportunities
Payment models, incentives and expanding state and federal insurance coverage	- Underinsurance and loss of insurance restricting transplant referral and/or limiting evaluation completion - Prescription plans with partial or lack of coverage of common transplant prescriptions resulting in large out-of-pocket costs - Vulnerable populations such as undocumented immigrants who do not receive benefits for comprehensive ESKD care	- Enhanced use of ESKD Treatment Choices (ETC)/Kidney Care Choices (KCC) models - Expansion of insurance coverage to include transplantation as an essential health benefit - Inclusion of pre-dialysis CKD care in Medicare coverage - Expansion of publicly funded insurance to cover chronic dialysis and transplantation for non-U.S. citizens across all 50 states
Policies to define practices	- Policies perpetuating racial and socioeconomic disparities - Insurance coverage	- Implementation of race neutral calculators across the transplant ecosystem that do not limit or interfere with access and readiness to transplant - Creation of policies to mitigate barriers to transplant informed by databases and registries (i.e., Early Steps to Transplant Access Registry, E-STAR)
Multiple transplant program waitlisting	- Fragmented, complex and multi-step evaluation process - Insufficient patient understanding and/or resources to pursue multi-listing - Large distance travelled to and from centers, cost, and repetitive testing when seeking multi-listing	- Provision of information and written materials explaining the multi-listing option as part of their evaluation process, and at each visit - Insurance carriers to uniformly allow multi-listing - Utilization of Telehealth in patients with geographic, financial, and logistical challenges to access different transplant centers - Centralized data repository accessible by multiple transplant centers

study, 239 recipients (median BMI = 41.4) were successfully transplanted using a laparoscopic robotic-assisted surgical technique that statistically reduced the risk of surgical site infection while maintaining patient and allograft survival outcomes comparable to national standards.[108]

4 | BARRIERS AND OPPORTUNITIES AT THE POLICY AND SYSTEM LEVEL (TABLE 3)

4.1 | Innovative payment models, incentives, and expanding state and federal insurance coverage

In 2019, the U.S. Department of Health and Human Services announced its *Advancing Kidney Health Initiative* (AKHI) aimed at early diagnosis and surveillance of kidney disease, and improving access to KT. The Center for Medicare and Medicaid Innovation (CMMI) under AKHI incentivizes KT via new payment models such as the ESKD Treatment Choices (ETC)/Kidney Care Choices (KCC) models. The ETC model tests the effectiveness of outcomes-based payments to increase home dialysis and KT including incentives for Pre-KT which is considered the "optimal KRT start." The KCC model supports early transplant education and replaces the fee for service-based care model.[109] CMS and Health and Services Administration are engaging organ procurement organizations, large donor hospitals, and transplant centers in a ETC Learning Collaborative to identify and spread the use of highly effective practices to increase the number of deceased donor KTs, decrease the national kidney discard rate, and increase the number of kidneys transplanted with a KDPI 60 or higher.[110] The Lewin group published its annual report on the impact of the ETC model in January, 2024. As of the second year, it has not had a measurable impact on transplant wait-listing. There were small and non-significant differences in live donor transplantation. There was a growth in the number of deceased donor transplants, but this does not follow a similar increase in waitlisting. It is unclear if the increase can be attributed to the ETC model.[111]

Expanding Medicare coverage to include earlier CKD stages and making KT an essential benefit for all policies will result in greater access to KT. Between 2006 and 2007, inadequate insurance coverage explained 11%–15% of all waitlist inactivations.[112] Patients with complex immigration status often lack adequate insurance. Under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Public Law 104—193), undocumented immigrants may not receive federal benefits including comprehensive ESKD care. Yet, non-U.S. citizens represent approximately 3.3% of the deceased donor pool.[113] There is a precedent for successful and sustainable models transplanting uninsured/underinsured patients in the states of Illinois and California. Expanding emergency Medicaid to include coverage of chronic dialysis and transplantation for uninsured patients regardless of citizenship across all 50 states, should be given not only because it is the most appropriate therapy for most ESKD patients but because it can result in substantial dollar savings for the healthcare system.

Every step to improve access requires resources and such responsibility should fall upon payors-federal, private, or other sources.

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Transplant centers in the long run cannot be expected to serve this role. Ultimately, the burden of payment is greatest among the least supported and those of lowest social economic groups. The responsibility for these patients should fall on the federal government and society overall. The healthcare system must provide greater support to those most in need and to those most hindered by barriers to access to kidney transplantation.

4.2 | Policies to help define practices

Our understanding of the barriers to referral and evaluation remain inadequate as this information is not traditionally captured in national data. The Early Steps to Transplant Access Registry (E-STAR) collected data from 13 states, >1800 dialysis facilities, and >30 transplant centers across 4 U.S. regions. Through these data, the understanding of disparities in pre-waitlisting steps can be identified and potentially intervened on. Using the E-STAR data, Patzer et al. identified dialysis facilities in Georgia with low referral rates, and subsequently tested a multi-level intervention to improve their referral rates. At one year, dialysis units receiving the intervention had nearly doubled referral rates (from 9.1% to 17.8%) This approach was noted to be about six times more effective among Black versus White patients.[114] Creating national registries to track transplant referrals, testing, and progression to waitlisting will improve our understanding of disparities to waitlisting, and foster research and quality improvement projects.[115]

There is a critical need to develop and disseminate best practices to reduce inactivation status on the waiting list. Recommendations from a NKF multi listing expert panel included: (1) optimize strategies to eliminate barriers to waitlist acceptance, including management of obesity, frailty, and deficiencies in psychosocial support, grounded in transparent communication of eligibility criteria to patients and referring clinicians; (2) develop and implement educational interventions that assist all patients, particularly members of racial and ethnic minorities, to successfully reach the waitlist expeditiously; (3) implement scalable and generalizable information technology solutions to support waitlist access and maintenance of transplant readiness.[27] Dedicated waitlist teams and use of technology as patient testing reminders can reduce waitlist inactivations.

The race neutral GFR calculation was introduced as the first step of restorative repairs to improve access for Black Americans to KT. By better identifying Black patients with advanced CKD, the proportion of patients educated and referred to KT increased.[116]

In addition to pre-waitlisting data, listing, delisting, and transplantation rates should be gathered at a national level for a better assessment of transplant access.[117] There is a large variability in delisting rates and mortality after removal from the waitlist. Improved data collection will help guide whether certain patients could benefit from remaining on the transplant list.[118] Greater transparency for patients in the kidney transplant process is desperately needed as patients need to know about their probability of reaching the waitlist, organ offer decision making, and likelihood of getting transplanted once listed.

4.3 | Leveraging multiple listing

Patients can list at multiple centers to increase their chances of getting transplanted. With the new broader distance-based allocation, multi-listing continued to increase the likelihood of receiving DDKT and lower the incidence of wait-list mortality. It, however, continues to disadvantage patients with racial/ethnic, socio-economic, and geographic barriers.[119] Programs are required to provide patients with information explaining multi-listing. However, not all patients fully comprehend it.

Efforts to address inequities by offering financial support such as housing and travel expenses, and lobbying insurers to cover additional evaluations should be made while we continue to offer multi-listing to our patients. Insurance carriers should uniformly allow and encourage multi-listing. CMS can and should expand existing value-based care models and incentivize nephrologists and dialysis providers to perform (and be reimbursed for) the medical testing needed for transplant evaluations.[119,120] Maintaining robust telemedicine,[75] coupled with the development of a HIPAA-compliant centralized patient data repository could facilitate multi-listing by reducing redundant testing, time, and expense.[121]

4.4 | Emphasizing living donor transplantation at every level (Table 4)

Living donor KT provides superior outcomes. Unfortunately, potential recipients are often unable to identify a LD. Concerns about post-donation health and/or financial burden to the donor are common barriers. Emphasis on living donation needs to be foremost and occur at every step in the transplant process. Patients should be educated about living donation whenever possible. Patient navigators can help motivate patients to pursue transplant and living donation.[122]

Removing disincentives to living donation is imperative. LDs often bear the cost of transportation, lodging, meals, lost wages, and dependent care. The National Living Donor Assistance Center (NLDAC), a federally funded program provides financial support to LDs. It reimburses expenses related to donation for those demonstrating financial hardship. It is largely underutilized and in 2017, only 9% of the LDKT were facilitated by NLDAC despite 50% of U.S. households meeting criteria.[123] Programs need to make every effort to help eligible LDs avail of NLDAC assistance. Policy and funding changes could expand NLDAC's to move toward making living donation financially neutral. Raising the support cap above $6000, and adjusting it for inflation in the future may help donors, given that 21% of donors approached the spending cap. The requirement of recipient means to establish eligibility assumes that most donors are related to their recipients. A policy shift in reimbursing donors based on their own income is likely to provide more meaningful assistance to them.

The Living Donor Protection Act would further strengthen donor protections by preventing insurance discrimination and making living

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TABLE 4 Emphasizing living donor transplantation at every level.

Barriers	Opportunities
- Inability to identify an appropriate willing donor - Lack of awareness regarding post-donation health and/or financial burdens - Underutilization of Paired exchange due to cost, complexity, and degree of allosensitization - Financial disincentives and direct costs to kidney donation such as travel, dependent care, and lost wages	- Removal of financial disincentives to donation - Increase in utilization and expansion of NLDAC assistance, and including consideration for donor's financial hardship for eligibility - Passage of the Living Donor Protection Act - Peer navigators involved in patient education - Utilization of Telemedicine to improve the efficiency of donor evaluations and the pre-donation process. - Development of kidney paired donation (KPD) programs

donation a condition under the Family and Medical Leave Act. Finally, national policies incentivizing transplant programs to participate of KPD should be considered.

5 | CONCLUSION

Many barriers to timely and equitable KT remain. Resolving these barriers requires collective and multidisciplinary interventions that involve all stakeholders across the kidney care continuum. Building partnerships with patients, their networks, and their community providers is imperative to enable most opportunities for Pre-KT and living donation. Creating transparency in the recipient and organ selection process can help patients select the right transplant program. for their work up and in that exercise, make the listing process more efficient. Transplant programs should normalize the use of KPD and consider innovative desensitization schemes combined with KPD to capitalize on every chance of living donor KT. While far from perfect, kidney transplantation remains the best available treatment for advanced kidney disease and patients deserve to have ample chance to succeed at it.

AUTHOR CONTRIBUTIONS

Angie G. Nishio Lucar: Concept/design; data analysis/interpretation; drafting article; critical revision of article; approval of article; final review and submission. **Ankita Patel and Ronald F. Parsons:** Concept/design; data analysis/interpretation; drafting article; critical revision of article; approval of article; final review. **Shikha Mehta:** Concept/design; drafting article; approval of article; data analysis/interpretation. **Anju Yadav; Mona Doshi; Megan A. Urbanski; Beatrice P. Concepcion; Neeraj Singh; M. Lee Sanders; Arpita Basu; Jessica L Harding; Ana Rossi; Oluwafisayo O. Adebiyi; Milagros Samaniego-Picota and Kenneth J. Woodside:** Concept/design; Data analysis/interpretation; drafting article; approval of article. With the exception of Angie G Nishio Lucar; Ankita Patel and Ronald F Parsons; all the other authors participated in similar manner.

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CONFLICT OF INTEREST STATEMENT

The authors declare that the manuscript was performed in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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