



# Amplifying the Patient Voice: Key Priorities and Opportunities for Improved Transplant and Living Donor Advocacy and Outcomes During COVID-19 and Beyond

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## Abstract

**Purpose of Review** To define patient advocacy and engagement for modern transplant and living donation care, particularly in light of the COVID-19 pandemic, describe the patient experience when transplant advocacy and engagement are optimized, and recommend opportunities for advocacy within three key areas: (1) including the patient voice in healthcare decisions and drug development, (2) access to the best evidence-based treatments and informed decision-making, and (3) present and future care innovations and policies.

**Recent Findings** There are many avenues for transplant and living donation advocacy and engagement at the patient, provider, family, system, community, and policy levels. Key recommendations include the following: (1) simplifying education to be health literate, written at the appropriate reading level, culturally sensitive, and available in multiple languages and across many delivery platforms, (2) inviting transplant patients and donors to the conversation through advisory panels, consensus conferences, and new mediums like digital storytelling and patient-reported outcomes (PROs), (3) training all members of the health team to understand their role as advocates, and (4) advancing policies and programs that support the financial neutrality of living donation, and support recipients with the cost of immunosuppressive drugs. Key recommendations specific to the COVID-19 pandemic include providing up-to-date, health literate, concise information about preventing COVID-19 and accessing care including telehealth.

**Summary** Enhancing advocacy and engagement for transplant patients and donors along the pre-to-post transplant/donation continuum can improve clinical outcomes and quality of life generally, and more so, in light of the COVID-19 pandemic.

**Keywords** Patient advocacy · Patient engagement · Transplant · Living donation · Patient education · COVID-19

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## Introduction

Although the term patient advocacy first emerged as a clinical standard of practice to protect patients against potential harms, over the past decade, it has evolved to encompass a much broader definition affecting the entire field of transplantation and living donation [1]. During the COVID-19 pandemic especially, patient advocacy has become imperative to protect the lives of patients who require or have received a transplant and who are at a high risk for poor COVID-19 associated outcomes due to their immunosuppressed status, need for regular medical visits, and comorbidities [2]. COVID-19 exposure during healthcare encounters is also a consideration for living donors. Patient advocacy is based on the belief that patients have “the right to select values they deem necessary to sustain their lives; the right to decide which course of action will best achieve the chosen values; and the right to express their values without coercion by others [3].” The sister term, patient engagement, is defined as the active process of ensuring that the patient’s experience, wisdom, and insight are infused into individualized care and within the design and refinement of care systems [4, 5]. When patients are truly engaged and advocate for their own health, their voices are sufficiently amplified to be able to clearly communicate which healthcare priorities are most important to them for inclusion in the design of the healthcare practices and systems. The focus of patient advocacy is on maximizing health and wellness, not just preventing and treating disease.

In organ transplant, there are multiple avenues for advocacy (i.e., protect the patient and their rights, improve communication between patients, families, and providers, activate a network of support for patients, establish healthcare systems and federal policies that serve patient needs, and deliver high-quality and consistent care during the COVID-19 pandemic). These will also help minimize risks of disease transmission [1, 6, 7]. The authors invited patients who have served on a patient advisory board in previous studies to form a panel for the purposes of this project to amplify the patient voice. Patients who accepted the invitation were asked to comment on their personal experiences with barriers they have faced in their transplant experience. The panel also provided recommendations to overcome these barriers. Guided by the framework of the socioecological model [8–11], our team of researchers and transplant recipients discusses optimal patient advocacy across the levels of the Model, key barriers, and suggestions to optimize the patient experience and improve advocacy both generally and in light of the COVID-19 pandemic.

## What Could Optimal Patient Advocacy Look Like?

“I’m an e-patient: equipped, enabled, empowered, engaged. I’m no clinician, but I do everything in my power to help

them, to play an active role in my own care, and even in the design of care.”—Dave deBronkart, cancer survivor and participatory care advocate [12].

If optimized, patient advocacy and engagement can address many unmet needs of the patient, their family, and the way the transplant team/systems cares for the patients (Table 1). At the patient level, before transplant, optimal advocacy entails patients feeling prepared and empowered to voice their concerns and needs. The provider is prepared to take physical, psychological, and financial wellbeing into consideration in all options for donation and treatment decision within an optimal system. Specific to COVID-19, optimal advocacy translates to patients feeling informed about organizational precautions being taken to promote safety and prevent the spread of disease, up-to-date policies that may affect their decision-making (i.e., how temporary waitlist inactivations impact transplant access or pauses in living donation surgery). Prospective living donors should also receive robust support and education regarding the risks and benefits to make informed decisions. For example, in kidney transplant generally, potential living donors’ concerns about the risk of later developing end stage kidney disease (ESKD) post-donation should be addressed in plain language. Prior to the COVID-19 pandemic, such education highlights recent research showing that the risk of subsequent kidney failure following donation is extremely small [14, 15]. However, in light of the pandemic, education should explain measures that the center is taking to prevent them from contracting COVID-19, and associations between acute kidney injury (AKI) risk and COVID-19 [16, 17].

In addition, optimal advocacy empowers donors and recipients to make long-term accommodations and a caregiver plan for their recovery. This is imperative during the COVID-19 pandemic when caregivers may experience additional burnout due to the new challenges of running errands for the immunocompromised transplant recipient that may increase caregivers’ exposure, of finding accurate health literate information and of understanding telehealth access and coverage. Individualized, data-driven care plans created in partnership with patients are a form of optimal advocacy and engagement. These plans involve continued support of holistic wellness and health-related quality of life for both recipients and donors. For recipients, they help ensure the new organ is maintained and the medication regimen is optimized. For donors, they help ensure that they fully recover and return to pre-donation life. Providers should do the following to optimize advocacy: maintain patient follow-up to the extent possible during the COVID-19 pandemic in accordance with UNOS policy to lower the number of patients falling through the cracks in the context of COVID-19, counsel patients about telehealth options and ensure patients know when an office visit is necessary, and prioritize COVID-19 testing access for transplant patients and living donors. When safe to do so in light of the COVID-19 pandemic, living donor outcomes

**Table 1** Barriers and opportunities for improving advocacy in transplant and living donation

Modifiable transplant barriers	Advocacy steps needed
Multiple levels	
Transplant education resources that are too complex	Providers advocate for standardized, health literate educational resources to be created to ensure patients are able to make informed decisions. The resources should be made available for print, online, video, etc. and with optimization for mobile devices. Transplant centers assign a patient advocate to comprehensively review all education and track these conversations to help improve the process and educational resources based on patient feedback.
Patient level barriers	
Low health literacy of patients precludes participation	Leave time during appointments for patients to ask questions. Ask patients to co-create a care plan using interactive worksheets or bookmarks integrated into their electronic medical records. Provide education in smaller modular steps for patients and caregivers.
Lack of transportation	Professional organizations show support for public programs and social work teams should make patients aware of available programs, resources, and assist with applications for potential transplant recipients/donors, and recipients/donors. Centers should consider a mobile unit, satellite office or telehealth options to assist patients in rural areas.
Underinsured or uninsured	Care coordination team assist with enrolling patients in public insurance and provide thorough education on dialysis and transplant coverage.
Less access for racial/ethnic minorities	Care teams push for use of a tool, like the Kidney Transplant Derailers Index (KTDI) [13], to identify patients at risk of not passing evaluation early and provide tailored resources. Provide care team with culturally sensitive education to address implicit biases and ensure equity across racial/ethnic minorities.
Low self-efficacy	Healthcare providers utilize motivational interviewing techniques during appointments and refer patients to care coordination to support patients with complex socioeconomic barriers that affect self-efficacy. Add a licensed therapist to the team to better meet patient needs and provide regular follow-up and support through the process.
Medical mistrust	Teach providers to acknowledge the patient as an active participant in creating the care plan to encourage adherence and patient empowerment. Provide patients with access to transplant advocates or mentors who have experienced the transplant process to follow up after the initial evaluation.
Medication side effects	Ensure providers engage post-transplant patients in conversations regarding managing side effects and teach providers to advise patients that adjustments can be made to their medications and the different side effects and trade-offs associated with changing the medication regimen. Research should focus on creating new medications with fewer side effects.
Work schedule precludes attendance of medical appointments	Transplant team should explore creative solutions like extended clinical hours in morning or evening, free childcare provided on site during visits, at home tests, telemedicine, etc.
Psychological support post-transplant	Social work team assists patients with immediate clinical needs and connects patients with long-term low-cost/free mental health support, especially with providers with expertise working with transplant patients and donors. Transplant centers run support groups or offer mental health support through apps or telemedicine.
Post-transplant financial planning	Care coordination team to co-create a financial plan that ensures knowledge of physical and mental recovery process post-transplant and provides access to information regarding disability and employer sick leave.
Lack of awareness of higher risk for cancer-related illness or death post-transplant	Transplant programs to educate patients about their increased risk of specific cancers due to immunosuppressant medication usage, and the need for regular screenings for early detection and care. Promotion of post-transplant cancer educational resources for patients.
High risk of poor outcomes from COVID-19 <sup>a</sup>	In advance of visiting a healthcare provider to receive care, patients should seek out relevant information about what precautions their healthcare organization is taking to prevent the spread of COVID-19. Patients should use telehealth services where possible, and protect their health using personal protective equipment and increased handwashing.
Fear of contracting COVID-19, and hypervigilance against germs prevents patients from seeking care <sup>a</sup>	Providers should conduct more routine follow-up with patients to maintain patient care regimen to prevent disease. Patients should contact providers and their insurance company (if applicable) about telehealth options. Patients should seek increased social support from family and friends to reduce psychosocial stressors.
Family level barriers	
Lack of understanding of importance of caregiver	Transplant teams should advocate for creation of a Caregiver Guide (available electronically and in multiple languages) that includes resources such as in-home supportive services and paid family leave. Complete a social support worksheet with patients to help identify sources of support. Help patients and caregivers to understand the long-term lifestyle choices required for the immunosuppressed. Transplant team should explore creative solutions like extended clinical hours in morning or evening, free childcare provided on site during visit, or at home tests.

**Table 1** (continued)

Modifiable transplant barriers	Advocacy steps needed
Work schedule precludes attendance of medical appointments with patient	
Never invited to learn about being a living donor	Encourage patients to talk with family/friends/social support networks about donation, with ongoing support. Give examples of ways to start the conversation, and education they can take home for donors. Keep inviting family to participate in visits (when safe) and care plans.
Increased live and deceased donor restrictions and increased waitlist inactivations <sup>a</sup>	Organizations should create guidelines to mitigate restrictions such as increased donor testing for COVID-19 and screening for symptoms, and self-isolating pre-donation if possible.
High caregiver burden to adapt to telemedicine which increases burnout likelihood <sup>a</sup>	Organizations should provide clear, concise, up-to-date information in a centralized location easy for caregivers to locate and access. Provide information in modular format to allow caregivers to quickly find relevant education and resources.
Provider level barriers	
Insufficient transplant knowledge	Organizations and practitioner groups encourage participation in courses covering all aspects of the transplant and living donation process. Providers communicate with transplant professionals to ensure basic knowledge of roles and increase patient referrals to necessary support. Provide continuing education credits.
Lack of physical therapy support	Organizations provide access to educational resources for physical therapy to patients and caregivers via cost-effective delivery mechanisms such as group courses, printed education, mobile applications, etc.
Insufficient understanding of patient needs and abilities to access telehealth <sup>a</sup>	Providers should engage patients, especially patients in vulnerable populations, in new and multiple ways such as providing information online, mobile friendly and also through text messages to overcome possible patient limited access to internet and other technologies.
System level barriers	
Disjointed healthcare system and loss to follow-up	Hospitals to push for early identification measures built into the electronic health record to help flag potential transplant candidates and connect them to resources. Improve primary care physicians' knowledge of early decline patterns and need to refer to a nephrologist.
Dialysis centers not motivated to encourage exploration of transplant options	Support requirements that limit funding based on demonstrated increase in patients waitlisted. Provide dialysis centers with a comprehensive transplant process and living donor education to encourage mastery of content and dissemination to dialysis patients early in the dialysis journey. Highlight success stories early on.
Patient is alone in tracking their adherence and outcomes suffer	Push for automation of treatment adherence tracking linked to electronic health record systems and apply health literate, patient-friendly tracking in patient-facing portals.
Community level barriers	
Lack of awareness about kidney health and preventable decline	Public education to encourage everyone to “know your numbers” and understand what kidneys regulate, and when kidney function is out of the normal range.
Lack of awareness of organ shortage or living donation	Awareness campaigns to help the general public know that there is a kidney shortage and that living donation can help.
Lack of health literate, centralized resource for up-to-date patient education and information for transplant patients <sup>a</sup>	Activate community resources explicitly specific to transplant patients through digital collaboration and telehealth. Provide concise messages at an appropriate reading level, avoid technical jargon, create action steps for the public, communicate honestly about known risks for transplant patients, and express empathy.
Public policy level barriers	
Work schedule precludes attendance of medical appointments	Advocate for policies that provide patients with sufficient sick time to continue with post-transplant care.
Loss of disability coverage post-transplant	Advocate for programs that support patients in successfully becoming financially independent and advocate for policies that protect patient's disability coverage until they are independent.
Out-of-pocket costs for living donors	Provide program development and resources (e.g. NLDAC) to patients and their prospective living donors. Develop and support programs that help with lost-wage reimbursement, travel, lodging and other out-of-pocket expenses available in an electronic portal for prospective living donors.
Out-of-pocket costs for recipient surgery, recovery, and ongoing care	Develop and support programs that help with lost-wage reimbursement, travel and lodging costs, ongoing co-pays.
Lack of novel care options to improve transplant outcomes	Encourage research of creative solutions to barriers that negatively impact patient experience, medication adherence, transplant longevity, etc.
Lack of long-term post-transplant education	Provide information about healthy living long after the initial recovery period, good habits for staying well, and where to go for questions.

**Table 1** (continued)

Modifiable transplant barriers	Advocacy steps needed
Loss of insurance, income and access to care as a result of the economic impact of COVID-19 <sup>a</sup>	Insurance companies should streamline/standardize access to telemedicine. Insurance companies should provide clear and up-to-date information about their coverage of telehealth services for patients.
Unclear insurance policies and Medicare regarding telehealth <sup>a</sup>	Insurance companies and Medicare should clearly communicate changes to policies that cover telehealth services. These changes should be sustainable so that transplant recipients can receive continued, uninterrupted care.

<sup>a</sup> This indicates COVID-19 related information about patient advocacy

should be tracked over the lifespan. Patients should have access to a multitude of pathways to care and COVID-19-relevant information including telehealth, digital health, and the current standard visits. Meeting the patient where they are, rather than exposing the patient to burden or risk to achieve high-quality care, should be the goal.

When advocacy is present, at the family level, patients and donors are encouraged to involve family in their care. Although many recommendations include encouraging family members to come along to provider visits, many hospitals and clinics restricted visitor policies to limit disease transmission risk during the COVID-19 pandemic—patients and families should have access to current visitor policies to help prepare for appointments. Nonetheless, in an optimal environment, the patient’s/donor’s family and friends are fully engaged in providing social support, clearly understand the responsibilities of being a caregiver (if applicable) [18], have the opportunity to take off work to attend the evaluation appointments when safe to do so, and learn about the transplant/donation process alongside the patient [19, 20]. Restrictions due to COVID-19 may require additional efforts to facilitate engagement of family/social supports in care plans. Social support from family and friends—even if provided through phone calls and video chatting—is especially important to help mitigate the negative psychosocial effects on recipients of fear of contracting COVID-19 and hypervigilance against germs.

At the provider and system levels, healthcare organizations and medical and professional schools create a culture of patient advocacy by training all healthcare team members to view themselves as advocates. These team members then provide patients and donors with high quality, health literate, culturally tailored education in multiple languages so they can self-advocate. Ideal information is up-to-date, empathetic, and accurate, about COVID-19 risks, resources, and actions for prevention. Transplant centers should create safe ways for non-symptomatic patients to visit the center. Through quality improvement initiatives, advocacy-focused system leaders identify barriers to their roles as patient advocates and track patient-care satisfaction using many patient-reported outcomes. Additionally, better means for patients to

communicate with the care teams in both the pre- and post-transplant and donation settings can help providers and systems achieve the highest quality care.

At the community level, optimal advocacy supports general public awareness of the need for donors, the opportunity to become living donors, the risks and benefits associated with living donation, and what transplant centers are doing to protect donors from COVID-19 in the healthcare setting. The public would be aware of ways they can do their best to safely donate during the COVID-19 pandemic [21•]. Research should continue to investigate the lasting effects of COVID-19 on renal function to determine donor eligibility. Churches and community groups may offer a primary outreach source for racial/ethnic minorities often not reached through traditional health education, by helping to share real-life stories and the need for living donors. Support groups should engage donors and recipients alike, and mentorship programs should be available for prospective candidates. Social media and public awareness campaigns help the public learn about organ donation and transplant. Making transplant-relevant apps available helps patients to spread the word about their need for a living donor. Communities need centralized resource hubs that would serve as an authoritative, trustworthy source of information about transplantation and donation in the context of COVID-19. Living donation should be normalized, appearing accurately in popular media and television, much like blood donation.

Finally, at the policy level, efforts should continue to advance policies to make living donation financially neutral and overcome insurance-related barriers affecting access to transplant, telehealth and immunosuppressant medications. For example, the Full House Committee on Energy and Commerce just passed the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act which extends Medicare coverage for immunosuppressive drugs beyond the 36 months that was formerly covered. Legislation such as this continues to make LDKT an available treatment option for those with ESKD by removing financial barriers. Lastly at the policy level, information about COVID-19 should be



congruent from each public source about the state of the pandemic, and how it is impacting donation and transplant care.

## Opportunities for Realizing Optimal Patient Advocacy and Engagement

Efforts should focus on three key areas for strengthening advocacy and engagement to make the above vision a reality: (1) including the patient voice in all healthcare decisions and drug development, (2) ensuring equitable access to the best evidence-based treatments and educate patients fully in their care decision process, and (3) honoring patient priorities in all care innovations and policies.

### Include the Patient Voice in Healthcare Decision-Making and Drug Development

To meaningfully include the perspectives and priorities of patients, providers and health systems must do more to invite and listen to their voices. Patient groups should be empowered to be part of the medical and scientific community through patient advisory groups, panels, and workshops [22]. Providers should listen to patient concerns and needs for information about COVID-19, including the voices of diverse patients from at-risk populations such as people of color and low-socioeconomic status patients who are at a higher risk of contracting and dying from COVID-19 [23, 24]. One example of providers and health systems listening to patients is exemplified in the public workshops held by the Food and Drug Administration (FDA) that invited recipients, family caregivers, and other patient representatives to share their experiences and frustrations with the side effects, cost and burden of immunosuppressant medication treatment [25]. Such workshops demonstrate that patients, donors, and families have important insights about the need for new drug development to address undesirable medication side effects, complexity of regimen, and need for constant follow-up. By recognizing and validating these patient priorities, the research community can begin to address gaps in care and unmet needs.

Additionally, by integrating patient-reported outcomes (PROs) into clinical systems, the patient voice can be indirectly captured through data, highlighting areas in need of improvement such as side effects or challenges adhering to complex regimens [26]. For example, PROs from clinical trials have shown high rates of symptoms post-transplant including and mental health-related symptoms (e.g., depression, anxiety, and fatigue) [27]. Development and validation of measures for transplant-related and donation-related PROs should be a patient advocacy priority.

Innovative platforms have also emerged to help capture the patient voice. For example, the Explore Living Donation Storytelling Project, a digital library of candid accounts by

donors, recipients, and their family members, showcases the power of digital media to help patients share about the aspects of transplant and donation that matter to them, the things they wish they had known, and the experience of receiving or donating a kidney [28]. Platforms like this not only help future patients and donors by providing a relatable resource but also can inform providers and researchers about the common questions, barriers to transplant and donation, or challenges that patients experience. These personal accounts also add emotional, cathartic and reflective value beyond just the didactic facts about transplant and living donation.

### Ensuring Equitable Access to the Best Treatments and Informed Decision-Making

To expand access to transplant and living donation, more people must be made aware of the option. Public service, social media campaigns, and television can help to enhance public knowledge and acceptance of living donation as a normalized act much like blood donation. In fact, many people first learn of living donation and transplant through television shows. Unfortunately, these shows can include inaccurate, dramatized, and controversial portrayals of transplant [29]. The field may benefit from more accurate and inspiring depictions of transplant and donation, like those in the new Donate Life Hollywood “Activate App,” for example [30]. Even inaccurate storylines can be an opportunity for continued conversation, factual correction by the field, and public engagement.

Before transplant or donation, all patients should be empowered and educated so that they can navigate the complex healthcare system successfully during the COVID-19 pandemic and beyond. Generally, patients have a vast amount of information to learn prior to transplantation. Kidney patients learn about the many treatment options, deceased donor kidney transplant (including non-standard deceased donor kidneys), living donor kidney transplant, and options for donor-recipient incompatibility (including kidney paired donation and desensitization) [31]. The challenge of consuming this amount of information is intensified during the COVID-19 pandemic and may be compounded by fear.

Patients require information that is health literate, concise, accurate, empathetic, and congruent sent through multiple communication channels. These should include innovative channels such as social media, text messages, and emails to ensure patients are receiving information in a timely and easy-to-access manner. This education must begin early so that patients have time to plan. In the case of kidney patients, ideally transplant education should occur prior to dialysis, yet for many patients the dialysis center is the first introduction to transplant. Unfortunately, many providers lack the knowledge and resources they need to successfully educate patients about transplant options [32, 33]. Centralized resource hubs, that can be designed to be patient-facing and/or

provider-facing including toolkits to help providers learn how to educate about transplant and also house current information about COVID-19 [34], best practice communities and mentoring programs, are all opportunities to create environments that support patient advocacy.

Additionally, priority should be given to creating health literate, culturally sensitive education written at no higher than the 6th grade level [35], yet much of the information about transplant is currently written above the 10th grade level [36, 37]. Education should also include guidance for how to share the need for living donors [38]. Educational resources such as the culturally relevant Spanish language website, *Infórmate* [39], support patient engagement. Unfortunately, in times of crisis like the COVID-19 pandemic, linguistically and culturally tailored translations may be delayed. Special focus on supporting disadvantaged groups is also needed. These groups include like racial/ethnic minorities and patients who face added barriers to transplant and living donation, such as multiple chronic conditions, inadequate social support, higher rates of being underinsured, and less likely to read or speak English [40–43]. For example, Sieverdes et al. found that African American patients reported many unaddressed concerns in pursuing living donor transplantation—the process was perceived as too difficult, too expensive, and too threatening to family or friends who might donate [44]. Education and advocating for improved supportive programs can help address these gaps.

Innovative delivery methods for education are also needed to ease the challenges associated with consistently updating transplant and donation information (including as impacted by COVID-19), as healthcare systems and busy providers often work in silos. Education that implements best practices, by delivering content in different ways to honor patients with different learning styles and presenting content in smaller modules over a longer period of time is most helpful [45]. Direct delivery interventions that supplement in-office education, including more intensive methods like home visits [46–48], as well as less intensive approaches like telehealth coaching, text messages, mobile applications, patient portals, and mail are also necessary [49, 50]. A properly designed, patient-focused digital health tool could assist patients in receiving general and up-to-date pandemic information including telehealth options, decision support, medication adherence, communicating concerns with their health team, connecting a family caregiver with a patient, and conducting routine visits.

Many transplant programs provide education about financial support and counseling. It is critical to make this education available to all patients and donors. This education should include resources about COVID-19 insurance coverage and Medicare, and can also provide psychological support, an area of high unmet need in pre- and post-transplant patients (<https://www.cms.gov/files/document/03052020-medicare-covid-19-fact-sheet.pdf>). However, barriers to telehealth will

persist until insurance companies and health systems agree on standard compensation rates for these services. The relative impact of the COVID-19 pandemic may likely change the standard of tracking and compensation related to working outside the clinic environment. Professional medical societies are playing an active role in prioritizing, funding, endorsing, and stewarding appropriate measures to improve transplant and education about the COVID-19 pandemic; they are advocating for new public policies to help patients.

Finally, patient advocacy also must continue to focus on simplifying the recipient and donor candidate evaluation processes. For example, patients with lower economic resources can be offered parking vouchers and one-day evaluations can be arranged for patients and donors traveling greater distances. The Kidney Transplant Fast Track and TALK intervention (Talking About Live Kidney Donation) are examples of programs trying to reduce barriers for minority groups to make it through transplant/donor evaluation successfully by reducing the number of medical visits [51]. Charitable foundations and hospitals offer assistance and a home-away-from-home option to help donors and recipients who must travel to the transplant center.

### **Honoring the Priorities of Patients in Care: Innovations and Policies**

For future care innovations and drug development, patient advocacy must ensure that physicians, programs, and health systems are willing to focus on outcomes important to patients. For example, patients have expressed that the outcomes important to them extend beyond survival and graft success and include measurements for graft health, cardiovascular disease, infection, cancer, and life participation [52, 53]. In a public meeting held by the FDA to understand perspectives of solid organ transplant recipients and their families, patients also express their need for more affordable treatment regimens, individually tailored treatment adherence interventions, and help building social support [25]. New patient needs and concerns are continually arising such as those related to COVID-19, and should not be overlooked during the pandemic or beyond.

The establishment of patient advisory boards may help healthcare systems to consider patients' perspectives and values in providing care throughout the treatment continuum [22]. Additionally, consensus conferences such as the American Society of Transplantation's Live Donor Community of Practice Consensus Conference on Best Practices in Live Kidney Donation [53] and living donor follow-up [54], are an opportunity to invite patients and donors to voice their priorities and collaborate with medical and research professionals.

Additionally, advocating for financial assistance programs and resources to help patients reintegrate into/participate in the workforce could provide the support necessary for patients to feel financially secure in pursuing transplant. There may be

other considerations that complicate workforce reintegration such as the economic impacts of COVID-19, and returning to a role that is meaningful and safe for the recipient. A recent policy advocacy goal to be celebrated is the extension of Medicare coverage of immunosuppressant medication recipient's life [55]. Research has demonstrated that extending Medicare coverage of immunosuppressant medications is associated with increased transplantation rates for low-income ESKD patients [56]. Since racial and ethnic minority patients are more likely to rely on public insurance like Medicare, temporary coverage of immunosuppressant medications impacted these patients more than White patients [57]. This new legislation may help to ameliorate this disparity.

Programs to help patients successfully (re)enter the workforce following the potential loss of disability insurance after they recover from transplant are also needed. Currently, 80% of ESKD patients are receiving or have applied for Social Security disability benefits [58]. A sudden loss of disability benefits has widespread effects on a patient's financial security—from paying rent to feeding their family. During COVID-19, providers should create formal documents to suggest that recipients who are immunocompromised work from home when possible. Patients may choose to forego transplant for fear of placing their families in financial peril.

Financial protections for living donors must also be a focus of advocacy efforts. Data suggest that on average, donors spend \$38,000 out of pocket to donate a kidney [59], and some individuals may refrain from donating a kidney due to the lack of reimbursement for lost wages and all out-of-pocket costs incurred from their donation [59]. Other financial disincentives include cost of travel and lodging at a transplant center, lost income due to kidney donation, cost of home/dependent care while donors are recovering from surgery, risk of dying from kidney removal, pain and discomfort of kidney removal, long-term health consequences of donating a kidney, and concern that a relative or close friend might need a kidney in the future [59]. This work has begun with legislation like the Advancing American Kidney Health Executive order and other non-profit programs which aim to assist all living donors by expanding eligibility criteria and reimbursable expenses covered by the National Living Donor Assistance Center like lost wages, and costs of dependent care.

## Conclusion

In conclusion, patient advocacy needs to focus on amplifying the patient's voice, helping them speak meaningfully about their experiences and needs throughout the pre- to post-transplant and living donation processes—these urgencies are magnified with the challenges posed by the COVID-19 pandemic. Patients should be empowered to be active participants in their clinical encounters and to take charge of their health outside of

the exam room. Patient empowerment is essential through the COVID-19 pandemic given changes in the healthcare system, and transplant recipients' increased risk of contracting COVID-19 and suffering negative outcomes. In addition, we need to identify and target the outcomes that matter to patients, which could coincide with those that matter to clinicians. We must simplify education and information about how care is impacted by the COVID-19 pandemic, and make it easily deliverable through innovative technology. At the system level, healthcare organizations should create patient advisory boards and invite patients and donors into the medical and research community, track patient experiences, provide more comprehensive long-term care, and establish standardized national performance metrics based on PROs. Patient advocacy is not simply a moral imperative. If we are acting as true patient advocates and empowering patients in their own healthcare, this commitment will result in more patients being alive and thriving—the entire purpose of healthcare itself.

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Papers of particular interest, published recently, have been highlighted as:

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