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## Understanding and Overcoming Barriers to Living Kidney Donation among United States Racial and Ethnic Minorities

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### Abstract

In the United States, racial-ethnic minorities experience disproportionately high rates of end stage renal disease, but they are substantially less likely to receive living donor kidney transplants (LDKT) compared with their majority counterparts. Minorities may encounter barriers to LDKT at several steps along the path to receiving LDKT including consideration, pursuit, completion of LDKT, and the post-LDKT experience. These barriers operate at different levels related to potential recipients and donors, health care providers, health system structures, and communities. In this review, we present a conceptual framework describing various barriers minorities face along the path to receiving LDKT. We also highlight promising recent and current initiatives to address these barriers, as well as gaps in initiatives, which may guide future interventions to reduce racial-ethnic disparities in LDKT.

### Keywords

race; ethnicity; disparities; minority; organ donation; barriers to living kidney donation; living donor kidney transplantation

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## Introduction

In the United States (US), racial-ethnic minorities experience disproportionately high rates of end-stage renal disease (ESRD) but are far less likely to undergo kidney transplantation than Whites<sup>1-3</sup>. Despite long-standing recognition of the need to reduce racial-ethnic disparities in transplantation, relatively little progress in identifying effective mechanisms to narrow disparities has been made<sup>1-3</sup>. Living donor kidney transplantation (LDKT) represents the optimal therapy for many patients with ESRD, providing numerous clinical benefits compared to prolonged dialysis or deceased donor kidney transplantation, including better patient and graft survival and improved quality of life<sup>4-5</sup>. LDKT also allows potential transplant recipients to bypass the lengthy deceased donor kidney transplant waiting list and therefore is a promising strategy for improving access to transplantation<sup>1, 6-7</sup>. However, over the past decade, minority ESRD patients have been consistently less likely than their majority counterparts to receive LDKT<sup>1, 6-11</sup>, limiting the promise of this therapy to address inequities in access to kidney transplants.

## Conceptual Framework: Barriers Limiting Minorities' Access to LDKT

To inform the development of effective interventions to improve racial-ethnic Minorities' access to LDKT, we must first elucidate barriers to living kidney donation and attempt to understand the mechanisms through which these barriers perpetuate disparities in access to LDKT. Studies suggest racial-ethnic minorities may encounter barriers at several steps along the path to successful LDKT, including during donor identification, transplant evaluation, and the kidney transplantation process itself<sup>12-32</sup>. Some minorities' willingness to pursue LDKT may also be heavily influenced by their concerns about post-LDKT challenges. These barriers to LDKT may be attributable to multiple factors, including recipient and donor attitudes, beliefs, and clinical characteristics<sup>12-21</sup>; health care provider knowledge, attitudes and behaviors<sup>22-26</sup>; and population awareness, attitudes, and disease burden<sup>27-30</sup>. A unifying framework describing barriers to living kidney donation could assist ongoing efforts and inform the development of future strategies to overcome barriers to living kidney donation. In this paper, we present a conceptual framework (Figure 1) that contextualizes barriers identified along the path to LDKT. We also review recent and ongoing initiatives to overcome these barriers, and we identify opportunities for the development of new strategies to reduce racial-ethnic disparities in LDKT.

### Barriers During Donor Identification

**Recipient, Donor Level**—Racial-ethnic minority ESRD patients may have knowledge deficits, concerns and attitudes which contribute to their increased difficulties identifying and approaching potential living kidney donors compared with their majority counterparts. Studies of African American and Hispanic patients have demonstrated their poor knowledge about the benefits of kidney transplantation and unmet concerns about surgical risks of LDKT for donors and recipients, which may hinder their willingness to approach potential donors<sup>13-14, 17, 33</sup>. Furthermore, African American potential recipients may experience high rates of psychological denial about the need for a kidney transplant<sup>14, 16</sup>, while Hispanic patients may be less likely to approach potential donors due to expectations that a relative would initiate an offer to donate<sup>13</sup>. As minorities consider pursuing LDKT, their concerns about graft failure and rejection rates, as well as potential health risks for living donors may also influence their willingness to identify and approach potential donors<sup>18, 20, 32</sup>. Additional barriers to donor identification for minority patients may include concerns about transplant medication costs (due to limited Medicare/insurance coverage) and potential medication side effects, as well as concerns about future financial risks, insurance eligibility, and medical coverage for their potential donors<sup>14, 35-36</sup>. Cultural biases and differences in family decision-making may also pose as additional barriers to identification of potential donors.

Recent data suggest older African Americans may be less likely to participate in LDKT due to concerns regarding the impact of living donation upon burial/cremation and spiritual well-being after death for living donors<sup>19</sup>. Asian Americans have also demonstrated more negative attitudes toward organ donation than Whites, including stronger cultural and religious concerns about maintaining body integrity after death<sup>47</sup>. Additionally, differential rates of clinical suitability may reduce the availability of minority potential donors and lead to disparate rates of LDKT<sup>21</sup>.

**Health Care Provider, Health System Levels**—Health care providers' perceptions of their patients' suitability and preferences for LDKT appear to differ according to patient race-ethnicity and may be associated with lower rates of LDKT education and transplant referral for minority patients<sup>22–23</sup>. Additionally, lower rates of preemptive physician-patient and physician-family discussions about LDKT among minorities likely reflect these inherent biases<sup>24–25</sup>. A recent study found that general nephrologists who primarily serve African American patients reportedly spent less time providing patients with LDKT education and counseling than counterparts who serve proportionately fewer African American patients<sup>26</sup>. These differences in provider-patient interactions may, in part, reflect variations in provider communication skills and cultural competence, knowledge about LDKT, and perceptions of patient suitability and preferences for LDKT<sup>22–26</sup>. Suboptimal quality of educational information about LDKT and lack of decision support regarding ESRD treatment options may serve as additional barriers to donor identification for minorities, but these issues have been poorly studied.

**Population, Community Level**—Currently, a majority of LDKT recipients receive kidneys donated by relatives or non-relatives emerging from recipients' close social networks. Unfortunately, evidence suggests that the disproportionately high burden of chronic diseases, particularly diabetes and hypertension, within racial-ethnic minorities' families and social networks may reduce the potential donor pool for many minority potential recipients<sup>27–30</sup>. For example, clustering of ESRD and associated risk factors has been noted within African American families, and first- or second-degree relatives of ESRD patients are at increased risk for developing ESRD<sup>27</sup>. Suboptimal community awareness about the benefits of and need for LDKT, as well as poor access to health care may serve as additional barriers to living kidney donation<sup>13</sup>.

### Barriers During Transplant Evaluation

**Recipient, Donor Level**—Although racial-ethnic minorities are less likely than Whites to complete the transplant evaluation process<sup>31</sup>, our understanding of specific barriers to successful completion of this integral step is limited. It is postulated that minority donor and recipients' concerns about surgical risks of LDKT combined with higher rates of obesity, diabetes, and hypertension among potential donors may contribute to lower rates of minorities completing the transplant evaluation process<sup>21, 31</sup>. Alternatively, economic constraints, including less flexibility to leave work for extensive transplant workup and recovery may also contribute to disparate rates of completing transplant evaluation.

**Health Care Provider, Health System Levels**—Although not restricted to LDKT, delayed receipt of nephrology subspecialty care prior to renal replacement therapy initiation has been associated with lower transplant referral rates, higher rates of incomplete evaluations, and reduced access to transplantation<sup>48–49</sup>. In a similar manner to donor identification, health care providers' perceptions of their patients' suitability for LDKT (and their inherent biases about patients' preferences for and adherence to medical therapies) may also lead to lower rates of transplant evaluation and higher rates of incomplete workups among minority potential recipients compared to Whites<sup>22–24</sup>. Additionally, emerging

research suggests possible links between inadequate health literacy and poorer ESRD outcomes, such as higher patient mortality<sup>39</sup> and lower rates of transplant evaluations<sup>38, 40</sup>. Notably, low health literacy has been shown to be highly prevalent among African American hemodialysis patients and may be associated with less access to kidney transplantation<sup>37–38</sup>. Further, average health literacy rates among Hispanic, African American, and American Indian/Alaska Native adults within the general population are reportedly lower than rates among Whites and Asian/Pacific Islanders<sup>41</sup>. Minimal availability and use of language and health literacy-appropriate educational resources about LDKT may contribute to minorities' higher rates of incomplete LDKT workups. Existing educational resources about LDKT may also lack important information that could alleviate minorities' concerns about the potential short-and long-term financial burden of LDKT<sup>14, 32</sup>.

**Population, Community Level**—Disparities in population disease burden and community resource allocation may also contribute to racial-ethnic differences in living kidney donation. For instance, historic differences in the racial composition of certain US geographic regions, such as in the Southeastern US are linked to well-documented differences in rates of chronic illnesses<sup>28–30</sup>. High rates of cardiovascular disease, hypertension, and diabetes in distinct regions of the Southeastern US where large populations of African American ESRD patients and their families reside may disproportionately limit the potential donor pool for this group compared with counterparts who reside in other US regions<sup>28–30</sup>. Transplant centers performing LDKT may also be more heavily concentrated in certain metropolitan regions. Data suggest African Americans living in rural areas may be less likely to receive transplants than their urban counterparts<sup>42</sup>. As evidenced by disproportionately lower kidney transplant rates in areas with higher degrees of poverty, minority patients and potential donors may also encounter more geographic and socioeconomic barriers to completing transplant workup<sup>43–45</sup>.

### Barriers During Kidney Transplantation

**Recipient, Donor Level**—Racial-ethnic minorities who complete transplant evaluation and workup might encounter additional barriers to successful LDKT, such as human leukocyte antigen (HLA) sensitization and ABO incompatibility<sup>46</sup>. Lower rates of preemptive LDKT referrals for minority patients, which result in higher rates of dialysis initiation, might contribute to higher rates of anemia and transfusion leading to HLA sensitization and higher burden of medical complications for minorities that impede successful LDKT<sup>24</sup>.

**Health Care Provider, Health System Levels**—Limited availability of blood-type compatible LDKT and less minority participation in paired kidney exchange programs may also contribute to disparate rates of LDKT<sup>46</sup>.

**Population, Community Level**—A number of recent federal and state policies have been enacted to provide financial support to living donors, including mandated sick leave from work and reimbursement for some living donor-related expenses; however, evidence suggests this legislation has not yet translated to increased rates of LDKT<sup>50</sup>. The extent to which racial-ethnic minorities who are actively considering LDKT are aware of these policies is unclear. Less awareness of these policies among minorities could be associated with demonstrated financial concerns about the LDKT process.

### Barriers After LDKT

**Recipient, Donor Level**—The long-term success of living kidney donation among minorities may be threatened by several factors. Current data suggest African American living donors may face increased risk of developing ESRD compared to Whites<sup>51,52</sup>. Low

health literacy, which is highly prevalent among minority adults<sup>41</sup>, may be associated with suboptimal transplant self-care and lower levels of kidney function among LDKT recipients<sup>34, 40</sup>.

**Provider, Structural Levels**—Reduced health care access, including poor availability or utilization of routine follow-up medical care and less health insurance coverage may also lead to suboptimal long-term clinical outcomes for minority living donors. Currently in the US, most living donor-related expenses are covered by the recipient’s health insurance. Notably, a significant proportion of living donors in the US also lack health insurance coverage at the time of LDKT<sup>35</sup>. Poor access to health care may be particularly prevalent among younger minorities<sup>53</sup>, possibly resulting in inferior rates of long-term healthcare follow-up and poorer clinical outcomes compared to Whites.

**Population, Community Level**—Lower socioeconomic status, less access to healthy foods, and resource deprivation may also contribute to suboptimal post-LDKT outcomes within racially-segregated minority communities<sup>54–55</sup>. For instance, a recent study of US Renal Data System and US Census data found that transplant recipients living in predominantly African American neighborhoods have inferior post-transplant outcomes (i.e. patient mortality and graft loss) compared with recipients living in neighborhoods with a lower percentage of African Americans<sup>55</sup>.

## Recent and Current Initiatives To Address Barriers To LDKT

A number of promising strategies to address barriers to living kidney donation at each stage of LDKT process currently exist (Table 1). We describe some of these initiatives, targeted at recipients and donors, health care providers and the health care system, and population and community factors.

### Recipient, Donor Initiatives

**Home, Community, and Clinic-Based Education:** A randomized trial evaluating the effectiveness of a home and community-based educational intervention to address concerns about living kidney donation found that patients who received the intervention were more likely to have had living donor inquiries than those who received standard clinic-based education<sup>33</sup>. Similarly, an ongoing study to develop a program tailored to patients’ level of transplant readiness will evaluate the effectiveness of conducting this educational intervention within the in-center dialysis setting<sup>56</sup>. **Social Network Engagement:** Lower LDKT awareness and knowledge among families and existing social networks might also contribute to less LDKT among racial-ethnic minorities. Increased community awareness and involvement of social networks beyond immediate family members in educational efforts may help to overcome these barriers for minorities<sup>57</sup>. A new initiative to engage potential LDKT recipients’ families, friends, or associates as ‘champions’ to help potential recipients raise awareness within their social networks regarding their need for a donated kidney may represent a promising strategy to overcome minorities’ difficulties approaching potential donors<sup>58</sup>. **Preemptive Transplant Education:** A recent randomized trial evaluated the effectiveness of a culturally sensitive educational and behavioral intervention designed to improve preemptive transplant education. The study found that the intervention, which incorporated social worker visits, educational videos and booklets, increased the pursuit of LDKT among participants<sup>59</sup>. Another study highlighted the importance of quality of life and health benefits of LDKT when designing interventions to improve preemptive transplant education<sup>60</sup>. **Financial Counseling:** The incorporation of social workers and financial counselors within educational efforts has also been shown to reduce patients’ financial concerns regarding the LDKT process<sup>32</sup>.

## Health Care Provider, Health System Initiatives

**Enhanced Provider-Patient/Family Education:** The Medicare Improvement for Patients and Providers Act of 2008 (MIPPA) aims to enhance timely provider-patient LDKT educational sessions and decision support for pre-ESRD patients<sup>61</sup>. **Standardized Training for Non-Transplant Healthcare Professionals:** Standardized education and training of health care providers not directly involved in the LDKT process (e.g. primary care providers and general nephrologists) could help to raise awareness of LDKT as a treatment option, reduce potential biases about patient suitability for LDKT<sup>22–23</sup>, enhance provider-patient LDKT communication, and increase rates of preemptive transplant referrals. The Medicare National Transplant Education Quality Improvement Initiative, which links dialysis facility quality measures to reimbursement, is one system-level intervention designed to improve rates of transplant education within in-center hemodialysis facilities<sup>61</sup>. **Paired Kidney Donation, HLA Desensitization, and ABO-Incompatible Programs:** Historically, high degrees of pre-sensitization and ABO-incompatibility have represented challenging immunological barriers to transplant among minority patients. However, wider adoption of paired kidney donation, HLA desensitization, and ABO-incompatible programs hold promise to overcome these challenges<sup>46</sup>.

## Population, Community Initiatives

**Increased “Neighborhood” Health:** Population-level interventions to improve the general health of underserved communities may help to decrease the disproportionate burden of chronic disease among minority populations. Examples of such efforts include increasing the availability of fresh, nutritious foods<sup>54</sup>, enhancing access to safe public spaces for exercise and recreation, reducing exposure to potential environmental toxins<sup>65</sup>, and implementing community-based screening programs for kidney disease and related risk factors<sup>66</sup>. **Satellite Transplant Centers:** Although future work is needed to determine the extent to which geographic barriers contribute to racial disparities in access to LDKT, it is postulated that certain minority populations might face unique challenges accessing transplant centers based upon their geographic distributions. To this end, a recent initiative found that bringing satellite transplant clinics to rural areas helped to address geographic and socioeconomic barriers and resulted in increased rates of transplant referrals for patients living in the Southeastern US<sup>45</sup>. **Federal and State Policies to Support Living Donors:** Federal and state legislation to support living donors, such as the National Living Donor Assistance Program authorized by the Organ Donation and Recovery Improvement Act of 2004<sup>67</sup>, and expanded Medicare coverage of immunosuppressant drugs may help to overcome potential financial barriers to LDKT.

## Next Steps: Future Work Needed to Narrow LDKT Disparities

Our conceptual framework highlights areas where future work is needed to further elucidate racial-ethnic barriers along the path to successful LDKT and lends insight to the development of future strategies to improve living kidney donation for minorities.

- **Expansion of efforts to understand barriers to donor identification among a more diverse range of racial-ethnic minorities.** To date, most studies identifying barriers to LDKT among racial-ethnic minorities have focused on potential recipient-related barriers occurring within the donor identification stage, particularly among African Americans and Hispanics. This work should be expanded to include studies of other minority groups such as Asians, Pacific Islanders, and American Indians/Alaska Natives who also experience disproportionately high rates of ESRD but are less likely to receive LDKT. More research is also needed to identify barriers to LDKT for potential living donors among all racial-ethnic groups.

- ***Improved understanding of racial-ethnic minorities' barriers to completing LDKT evaluation and workup.*** Work elucidating unique barriers that racial-ethnic minorities face in completing LDKT evaluation and workup could inform the development of effective interventions to overcome barriers in this phase of the LDKT process. Studies expanding our knowledge of how minority patients cope with advancing chronic kidney disease and studies further exploring the influence of family dynamics in diverse populations as related to rates of seeking transplants may be particularly helpful.
- ***Culturally sensitive and health literacy-appropriate educational resources to improve minorities' understanding of LDKT and transplant self-care.*** Because racial-ethnic minorities are disproportionately affected by inadequate health literacy, culturally sensitive educational interventions tailored to accommodate low health literacy could be particularly useful in improving potential recipients', their families', and their communities' knowledge and awareness about the risks and benefits of LDKT. Efforts to incorporate the importance of medication adherence and self-care within transplant-related educational materials may also help to reduce racial-ethnic disparities in LDKT outcomes.
- ***Improved characterization of racial-ethnic minorities' long-term clinical risks with LDKT*** Efforts to accurately quantify the short- and long-term health and economic consequences of living donation for minority living donors are needed to ensure long-term donor safety and well-being and to better inform potential recipients and donors about the risks associated with their pursuit of LDKT. Comprehensive surveillance systems are needed to enhance tracking of long-term health outcomes for donors of all races and ethnicities.
- ***Improved cultural competency and strengthened communication among medical professionals*** Strategies to help medical professionals identify their unconscious biases regarding patient suitability and preferences for LDKT may help to improve minorities' referral rates. Improving provider competence in communicating with racial-ethnic minority patients and families may also help to enhance the informed consent process and lessen minorities' mistrust of the LDKT process. Strengthened communication between transplant, dialysis, and primary care providers, as well as educational support from a multidisciplinary team of health professionals (e.g. nurses, physicians, pharmacists, nephrologists, surgeons) may also help to overcome existing barriers to living kidney donation.
- ***Community-based collaboration to enhance trust, awareness, and support for LDKT.*** Sustained and meaningful collaborations between medical-transplant professionals, religious leaders, and community organizations may help to foster patient and family trust in healthcare providers' recommendations for LDKT and raise awareness and social support for those considering LDKT within minority communities.
- ***Improved support for living donors post-donation follow up:*** To reduce donor concerns regarding post-transplant follow-up, policymakers should consider methods to enhance medical follow-up for living donors through increased access to health insurance coverage and primary care providers.

## Conclusions

Significant work has been done to identify barriers faced by racial-ethnic minorities in their pursuit of LDKT, and several initiatives have emerged to address these barriers. However, many of these initiatives are relatively new. Thus, evidence of long-term effectiveness and

optimal methods for implementing and disseminating these strategies are not yet clear. Rigorously designed studies that demonstrate the effectiveness of promising interventions to address specific barriers racial-ethnic minorities face along the path toward LDKT may guide policy makers, clinicians, and patients to utilize these interventions more broadly. Partnerships between patient advocacy groups, health care providers, and community organizations should be developed and leveraged to ensure the long-term sustainability of effective interventions.

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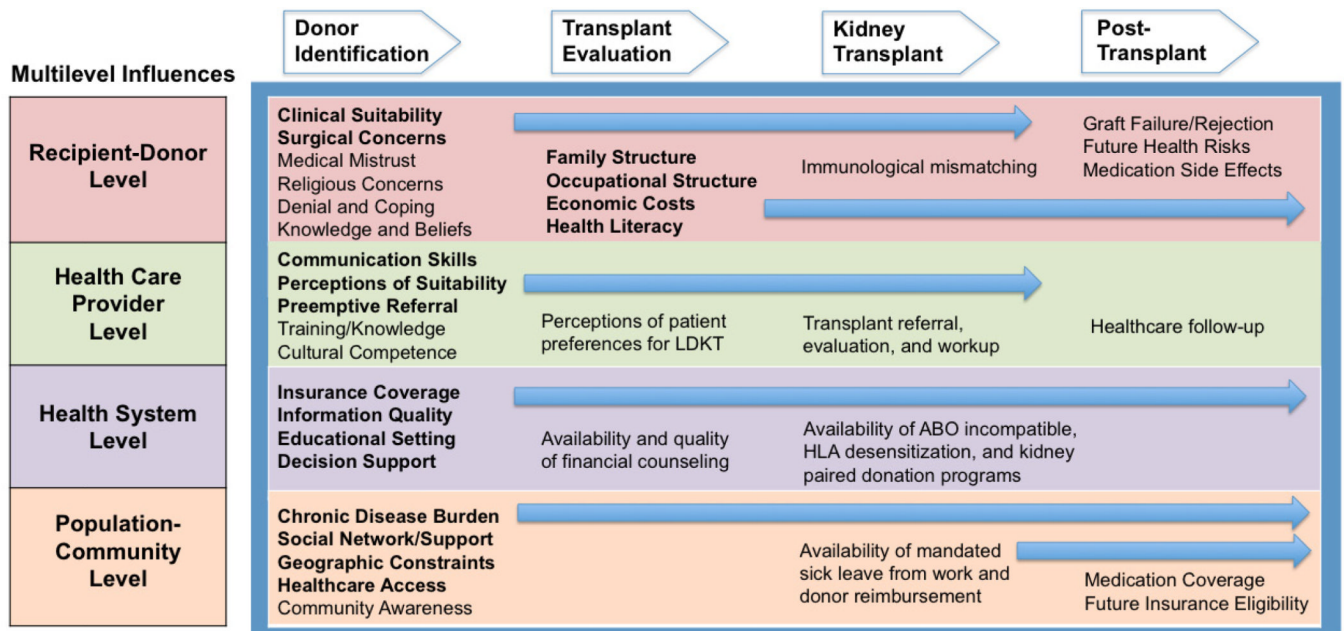
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### Summary Points

- Racial-ethnic minorities may encounter barriers to living kidney donation at distinct steps in the transplant process including during donor identification, transplant evaluation, surgery and post-transplantation.
- Determinants of living kidney donation operate at contextual levels beyond just the potential recipient or donor.
- Strategies that address barriers to living kidney donation at the level of the potential recipient, donor, health care provider, health care system and/or community network are currently under investigation.
- Rigorously designed clinical trials that test the effectiveness of promising interventions are needed to guide broader dissemination and adoption.
- Additional studies are needed to address low rates of living kidney donation within less-studied racial and ethnic groups (e.g., Asians, Hispanics, American Indians/Alaska Natives, Pacific Islanders).



**Figure 1.** Multilevel Influences Contributing to Barriers to Living Kidney Donation for Racial-Ethnic Minorities at Each Stage of the LDKT Process

Table 1

## Promising Initiatives to Address Barriers to Living Kidney Donation for Racial-Ethnic Minorities

	<b>DONOR IDENTIFICATION INITIATIVES</b>	<b>TRANSPLANT EVALUATION INITIATIVES</b>	<b>KIDNEY TRANSPLANT INITIATIVES</b>	<b>POST-TRANSPLANT INITIATIVES</b>
<b>RECIPIENT-DONOR INITIATIVES</b>	<ul style="list-style-type: none"> <li>• Culturally-sensitive home and community-based education<sup>33</sup></li> <li>• Programs to educate and engage patients' families and social networks<sup>57-58</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Financial counseling to address insurance/k economic concerns<sup>14, 32</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Educational/behavioral interventions to improve preemptive transplant education<sup>59-60</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Cultural, literacy, and language appropriate efforts to support patient self-care</li> </ul>
<b>HEALTH CARE PROVIDER INITIATIVES</b>	<ul style="list-style-type: none"> <li>• Enhanced provider-patient/family LDKT education/family<sup>56, 61</sup></li> <li>• Cultural competency and racial diversity of healthcare providers<sup>62</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Educational support from heterogeneous team of health professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Improved healthcare access and continuity of care</li> </ul>	<ul style="list-style-type: none"> <li>• Long-term medical follow-up for living donors</li> <li>• Pharmacist-led counseling about medication therapy and adherence<sup>34</sup></li> </ul>
<b>HEALTH SYSTEM INITIATIVES</b>	<ul style="list-style-type: none"> <li>• Standardized transplant education and training for non-transplant medical professionals<sup>23</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Partnerships with non-healthcare professionals to enhance social support</li> </ul>	<ul style="list-style-type: none"> <li>• Paired kidney exchange programs<sup>46</sup></li> <li>• HLA desensitization and ABO incompatible programs<sup>46</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Comprehensive tracking and health-related monitoring of living donors</li> </ul>
<b>POPULATION-COMMUNITY INITIATIVES</b>	<ul style="list-style-type: none"> <li>• Community-based partnerships to promote awareness and trust in minority communities<sup>64</sup></li> <li>• Increased availability of healthy foods, safe physical activity space, and community health screenings<sup>54, 65-66</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Satellite outreach transplant centers to address potential geographic barriers and enhance rates of transplant referral in rural areas<sup>45</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Federal and state policies to support living donors<sup>50, 67</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Expanded medication coverage and access to primary healthcare<sup>63</sup></li> <li>• Policies to ensure future insurance eligibility for living donors<sup>35-36</sup></li> </ul>