Chapter 23
Racial Disparities in Kidney Transplant and Living Donation

Tanjala S. Purnell and L. Ebony Boulware

Disparities in the Need for Kidney Transplantation

The rapidly increasing prevalence of end-stage renal disease (ESRD), characterized by the failure of kidney function, has generated national efforts to alleviate the public health burden of this life-threatening condition. Currently, approximately 560,000 US adults are treated for ESRD, a condition that results in poor survival, poor health-related quality of life, and high health care costs [1]. Although patients with ESRD comprise less than 1% of Medicare beneficiaries, they account for over 6% of Medicare spending, resulting in estimated costs to Medicare of over $ 20 billion annually [1, 2].

An estimated 26 million adults in the U.S. currently have some degree of kidney damage [3], a major risk factor for the development of ESRD. Racial–ethnic minorities are substantially more likely to develop ESRD than Whites [1, 4, 5]. Adjusted rates of ESRD among African-Americans, Native Americans, and Asians are significantly higher than rates of ESRD among Whites [1] (Fig. 23.1), and ESRD rates among Hispanics are also significantly higher than rates among non-Hispanics [1] (Fig. 23.2). Compared to Whites, African-Americans experience up to fourfold greater risk of developing ESRD [1]. African-Americans and Hispanics account for approximately 47% of the ESRD population, while comprising only 28% of the overall US population [1, 6].

Disparities in rates of ESRD have been attributed to a multi-factorial combination of genetic, environmental, cultural, and socioeconomic influences [7]. Diabetes and hypertension are the leading causes of ESRD (accounting for over 70% of the reported ESRD cases in the U.S.) [1], and these diseases disproportionately impact racial–ethnic minorities. Other causes include HIV infection, sickle cell disease,

---

T. S. Purnell (✉) · L. E. Boulware
Department of Medicine/General Internal Medicine, Johns Hopkins School of Medicine,
2024 E. Monument Street, Suite 2-600, 21205, Baltimore, MD, USA
e-mail: tpurnel1@jhmi.edu

L. E. Boulware
e-mail: lboulwa@jhmi.edu

J. Steel (ed.), *Living Donor Advocacy,* DOI 10.1007/978-1-4614-9143-9_23,

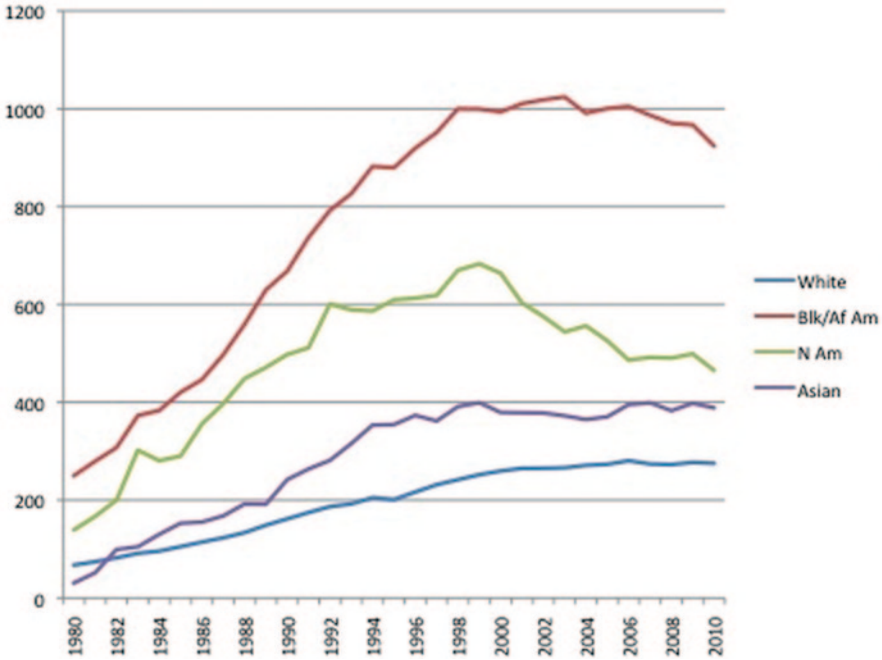

Fig. 23.1 Adjusted rates of end-stage renal disease (ESRD) by race (1980–2010). Incident ESRD patients. Adjusted for age/gender. (Reference: 2005 ESRD patients. Data Source: US Renal Data System, USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2012)

systemic lupus erythematosus, heroin abuse and/or dependence, kidney stones, chronic kidney infections, and certain cancers [1].

Disparities in Access to Kidney Transplantation

Patients with ESRD require replacement of their kidney function (in the form of dialysis treatment or kidney transplantation) to sustain life. While dialysis is currently the most common therapy used to treat ESRD, kidney transplantation offers patients improved life expectancy at less cost than that for dialysis care [1, 8]. Kidney transplantation is also associated with improved mental health, physical functioning, social functioning, and other quality of life measures, such as the ability to travel and work when compared to patients receiving dialysis treatment [9–12]. Yet, the number of persons on the waiting list for a transplant greatly exceeds the number of available kidneys. Racial–ethnic minorities with ESRD have persistently lagged behind Whites with respect to both placement on the waiting list for deceased donor

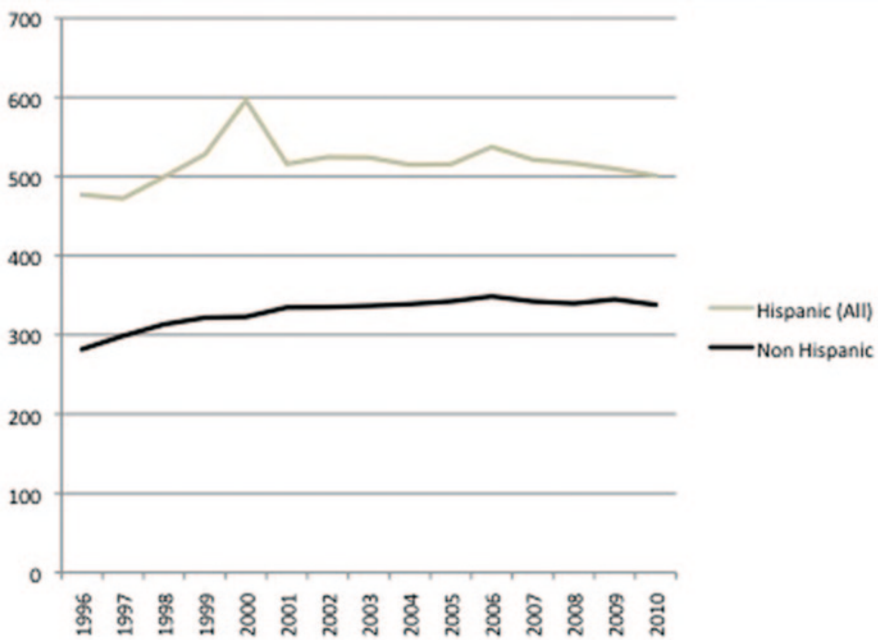

Fig. 23.2 Adjusted rates of end-stage renal disease by Hispanic ethnicity (1996–2010). Incident ESRD patients. Adjusted for age/gender. (Reference: 2005 ESRD patients. Data Source: US Renal Data System, USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2012)

kidneys and receipt of deceased donor transplants [1, 4, 13–16] (Fig. 23.3). In 2010, although the rate of deceased donation was 28.1 among African-Americans compared to 21.4 among Whites, the rate of patients receiving transplants from deceased donors was only 2.0 among African-Americans compared to 2.6 among Whites [1].

Racial–ethnic disparities in rates of deceased donor kidney transplants have been attributed to several factors, including immunological incompatibility of deceased donor kidneys, lower rates of referral of racial–ethnic minorities for transplantation, inadequate transplant workup for minorities referred for transplants, human leukocyte antigen (HLA)-mismatching, sociodemographic barriers to the completion of pretransplant steps, disproportionate access to health care, and patient concerns about potential risks associated with transplantation [15–29]. Recent estimates show that American Indians/Alaska Natives, African-Americans, and Hispanics are less likely than Whites to be listed for kidney transplants [4]. Once listed for transplantation, racial–ethnic minorities have been shown to wait longer for kidneys than Whites [1]. For instance, among first-time wait-listed patients registered in 2007, 48.6 % of African-Americans and 43.8 % of Asians were still waiting for a transplant after 3 years, compared with only 34.5 % of White patients [1]. Uninsured patients and those of lower income levels, who also tend to be disproportionately

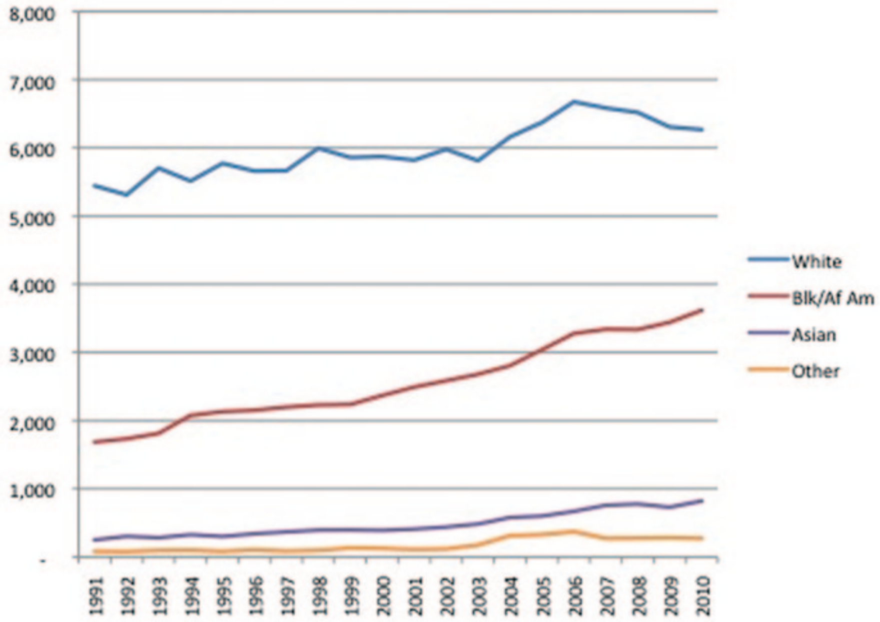

Fig. 23.3 Deceased donor transplants by race (1991–2010). Patients age 18 and older. Includes kidney-alone and kidney-pancreas transplants. (Data Source: US Renal Data System, USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2012)

made up of racial–ethnic minorities [30], are also less likely to be listed for kidney transplantation.

Potential Role of Living Donation in Narrowing Disparities

Patients with progressing chronic kidney disease, those with newly diagnosed ESRD, and those already on waiting lists for deceased donor kidney transplants may increase their chances of receiving a transplant by also pursuing living donor kidney transplantation (LDKT), in which an ESRD patient receives a kidney from a living friend, family member, or other altruistic person. LDKT is 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 [12, 31, 32]. LDKT also provides a mechanism through which patients may bypass lengthy waiting times on deceased donor kidney transplant waiting lists and therefore significantly decrease waiting times for transplants.

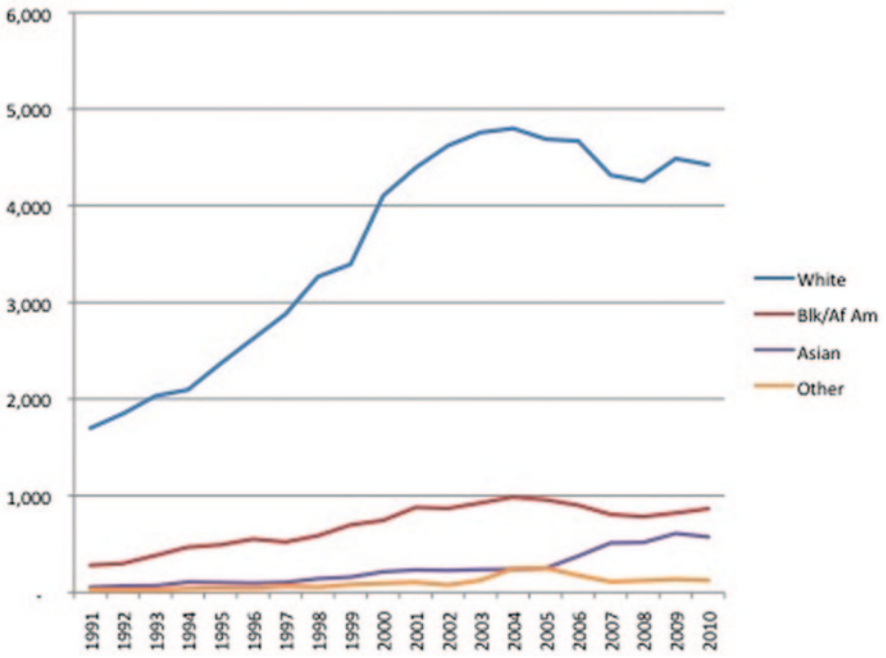

Fig. 23.4 Living donor transplants by race (1991–2010). Patients age 18 and older. Includes kidney-alone and kidney–pancreas transplants. (Data Source: U.S. Renal Data System, USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2012)

Barriers to Living Kidney Donation for Racial Minorities

Despite the potential benefits of LDKT, minority ESRD patients have been consistently less likely than Whites to receive LDKT over the past two decades (Fig. 23.4), thus limiting the promise of this therapy in addressing inequities in access to kidney transplants [1, 4, 33–35]. For example, recent data show that African-Americans and Hispanics accounted for only 27.5 % of the total LDKT recipients in 2012, although they account for over 47 % of the ESRD patients [1, 35]. Evidence suggests that racial–ethnic minorities experience unique barriers that contribute to disparities in LDKT at the patient or potential-donor level (e.g., beliefs, concerns, and clinical characteristics) [36–44], health care provider/system level (e.g., decision support, information quality, and perceptions) [27, 45–49], and population-community level (e.g., social awareness, resource allocation, and disease burden) [50–52]. In addition, racial–ethnic minorities may experience these barriers during one or more of the four primary steps along the path to successful completion of LDKT: donor identification, transplant evaluation, kidney transplant, and posttransplant recovery [53]. The development of strategies to address disparities in receipt of LDKT requires a comprehensive understanding of these barriers that impede access to LDKT among racial–ethnic minorities in the U.S. We provide a detailed summary of barriers reported within the published literature later, and we also reference an evidence-based framework (Fig. 23.5) that contextualizes key barriers identified along the path to LDKT [53].

Patient-Related Barriers

Racial–ethnic minorities with ESRD may be more likely than their White counterparts to experience a number of patient-related barriers to receipt of LDKT, including unmet concerns about the physical, psychological, and financial risks associated with LDKT; patients' concerns about their ability to initiate LDKT discussions within their families; and less willingness to approach potential donors due to concerns about potential risks for living donors [41, 42, 46]. Studies of African-American and Hispanic patients have also identified poor LDKT knowledge, medical mistrust, and concerns about surgical risks of LDKT as potential barriers that may impede efforts to identify and approach potential live donors [37–40]. Alvaro et al. conducted focus groups of Hispanic patients and reported that lack of knowledge about living donation, concerns about potential harm to the donor, and expectations that a relative would initiate an offer to donate were identified as barriers to identifying and approaching potential donors [37]. A study by Pradel et al. also found that surgical concerns were associated with lower likelihood of considering LDKT, discussing LDKT with their family, or asking for a kidney in those receiving hemodialysis [40]. Evidence suggests that African-American potential recipients may also experience higher rates of psychological denial about the need for a kidney transplant [41, 43]. Results from a survey by Lunsford et al. suggest that African-Americans might cope with the need for a kidney transplant differently than non-African-Americans, and that African-American potential recipients may be less acceptable of and more likely to deny the need for a transplant [43]. This denial might affect persuasiveness or willingness to ask for live donation.

Concerns about the potential risks for living donors might also contribute to racial–ethnic minorities' reported difficulties identifying and approaching potential donors within their families, social networks, and communities. Boulware et al. reported that African-American patients were concerned about potential burdening of family members, potential donors' future health, and their future inability to donate a kidney to another family member who might need it, and feelings of guilt or coercing family members [41]. Within focus groups that included African-American and Asian potential transplant recipients, Waterman et al. also noted concerns about living donation, including feelings of guilt or indebtedness to the donor, harm or inconvenience to the donors, concerns that the potential donor might need the kidney later, and concerns over disappointing the donor if the transplant failed [42].

In addition to barriers encountered during donor identification, evidence suggests that higher rates of chronic illnesses, such as obesity, diabetes, and hypertension among racial–ethnic minorities may contribute to lower likelihood of completing

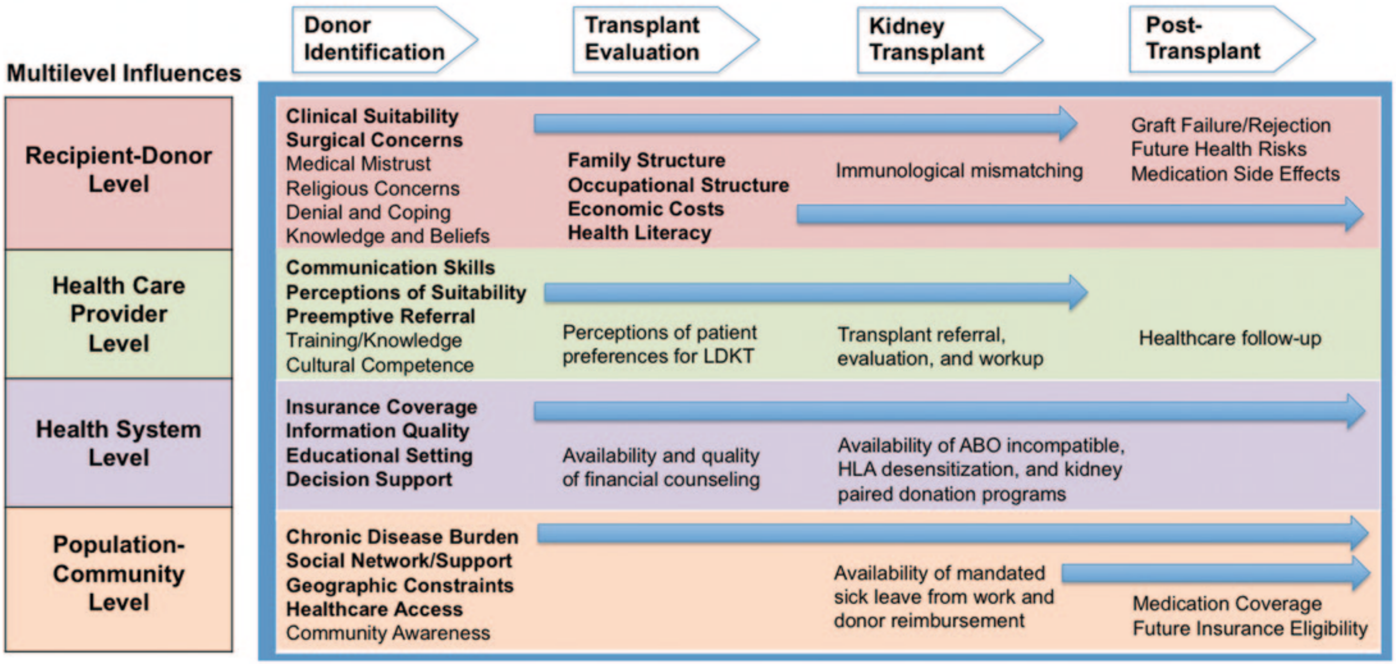

Fig. 23.5 Multilevel influences contributing to barriers to LDKT for racial–ethnic minorities. [54]

the transplant evaluation and workup process. In addition, racial–ethnic minorities who are able to identify a suitable donor and who complete the transplant evaluation process might also encounter additional barriers to transplant surgery, such as HLA sensitization and immunological incompatibility due to limited availability of blood-type incompatible LDKT programs [81]. Racial–ethnic minorities who successfully receive transplants may also experience unique barriers that threaten the long-term success of LDKT. Burke et al. found that African-American race and presence of diabetes adversely affected 10-year patient and graft survival among kidney transplant recipients within a study conducted at a single transplant center [54]. Douzdijan et al. also found that kidney graft survival was adversely affected by African-American race for transplant recipients [55]. In a study of patients who previously received transplants, Foley et al. also reported that kidney graft survival rates were significantly lower in African-American versus White recipients [56].

Potential Donor-Related Barriers

Difficulty identifying potential living donors has been shown to be a major contributor to racial–ethnic disparities in receipt of LDKT. Racial–ethnic differences in attitudes (e.g., cultural, religious, and surgical concerns) about and willingness to participate in live donation, less communication about LDKT within families, and lower tolerance for economic risks of live donation have all been implicated as potential donor-related barriers contributing to disparities in living donation [38, 39, 57]. Boulware et al. demonstrated that mistrust in hospitals and concerns about discrimination, as well as surgical concerns about living donation were associated with less willingness to donate living organs to relatives as noted within a national household telephone survey of potential donors among the general public [38]. Robinson et al. demonstrated within a survey of African-American potential donors that attitudes and beliefs toward donation were associated with self-reported willingness to become a living donor [39].

Short- and long-term economic risks of live donation may be associated with less willingness to donate, particularly among minority groups already disproportionately burdened by financial pressures. While a majority of direct medical costs associated with living kidney donation are covered by Medicare and/or private health insurance, live donors may still be faced with additional costs associated with the donation process, including lost wages due to time away from work, incidental medical expenses, transportation and lodging, and hired caregiver or child-care costs [58–61]. A study examining the long-term impact of live donation found that 19 % of live donors who participated in the study reported moderate financial problems after donating, and 4 % reported severe financial problems (such as lost work time, medical bills not covered by insurance, and other out-of-pocket expenses) [58]. In a study of living donors in the U.S., participants reported that financial costs incurred by the donor averaged $ 837 and ranged from $ 0 to 28,906 [62]. Potential donors' concerns about future insurability may also impact their willingness to donate. Findings from recent studies suggest that becoming a living donor may impact one's ability to obtain life, health, and disability insurance [60, 63]. A study of living donors in the U.S. found that while many insurance companies reported being willing to insure these individuals, a number of living donors have reported difficulties obtaining insurance coverage after donation [60]. Existing educational resources about LDKT may also lack important information that could alleviate minorities' concerns about the potential short- and long-term economic burden of LDKT.

In addition to barriers that contribute to disparities in the identification of potentially willing donors, some minorities who are actually willing to donate may not be healthy enough (i.e., clinically suitable) to complete the donor evaluation and surgical processes. Reeves-Daniel et al. performed a study of unsuccessful live kidney donations and found that African-American potential donors were more likely to be excluded due to obesity or failure to complete the transplant evaluation [49]. Tankersely et al. performed a study of inpatient donor and recipient evaluations and found that African-American patients were less likely than Whites to identify clinically suitable potential live donors at the time of evaluations due to higher rates of previously undetected comorbid medical conditions, such as hypertension among them [50]. A study of patients referred for potential live kidney donation by Lunsford et al. found that African-Americans were more likely to be lost to follow-up than non-African-Americans due to higher rates of incompatible blood types, high body mass index, or ineligible recipients [51].

Racial–ethnic minorities who complete the evaluation and surgical processes may also experience long-term risks after the transplant surgery. African-American living donors may face increased risk of developing ESRD and may be more likely than White donors to need a kidney in the future. Gibney et al. found that future risk of developing ESRD might be more exaggerated in African-American versus White donors within a study using organ procurement and transplantation network (OPTN) data [64, 65]. In a study to assess potential racial differences in posttransplant kidney function for living donors, Doshi et al. found that postdonation serum creatinine levels were slightly higher for African-American donors compared to Whites [66]. In a study of OPTN and administrative data, Lentine et al. found that after kidney donation, African-American and Hispanic donors had an increased risk of hypertension, diabetes requiring drug therapy, and chronic kidney disease, compared with White donors [67]. Nogueira et al. also found that African-American living kidney donors experienced a high incidence of hypertension and a modest drop in kidney functioning post donation in a study of long-term donor outcomes [68]. Within a study of national trends and outcomes following live kidney donation, Segev et al. reported that surgical mortality from live donation was higher in African-American donors compared with White and Hispanic donors [69].

Health Care Provider and System-Related Barriers

Racial–ethnic minorities' poorer access to routine health care, lack of provider–patient and provider–family discussions regarding LDKT, and health care providers' perceptions about minority patients' preferences and suitability for LDKT may be associated with lower rates of LDKT education and transplant referral for minority patients [27, 45–46]. Providers' views about the benefits of transplantation and beliefs about reasons for racial–ethnic differences in access to transplantation may affect how (or whether) they present LDKT as a treatment option to racial–ethnic minority patients. Ayanian et al. conducted a survey of nephrologists in the U.S. and reported that physicians were less likely to believe that transplantation improves survival for African-Americans than Whites [27]. African-American patients participating in the study were also less likely than White patients to report receiving some or a lot of information about transplantation. Within focus groups conducted to assess health care professionals' beliefs about barriers contributing to lower rates of donor identification for African-American patients, Shilling et al. revealed that providers noted lack of clinical suitability, financial concerns, reluctance to approach potential donors, surgical fears, medical mistrust, and less awareness of LDKT as potential barriers [45]. Suboptimal rates of patient–physician discussion and family–physician discussions about LDKT prior to ESRD may serve as additional barriers to donor identification among racial–ethnic minorities. Within a survey of African-Americans patients, spouses, and children, Boulware et al. found that despite most patients expressing desire for a transplant, only 68 % of patients and less than 50 % of their spouses had discussed transplantation with physicians [46]. 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.

Lower rates of transplant referrals and delayed receipt of nephrology subspecialty care prior to renal replacement therapy initiation have also been associated with higher rates of incomplete evaluations. Notably, Ayanian et al. found that African-American patients were less likely to be referred for evaluation at a transplant center, even after adjustment for patients' preferences and expectations about transplantation, coexisting illnesses, or socioeconomic factors [21]. Health care providers' perceptions of 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 [21]. Ayanian et al. conducted a survey of nephrologists in the U.S. and reported that physicians were less likely to believe that transplantation improves survival for African-Americans than Whites, and more likely to believe that disparities in rates of transplant were due to differences in patients' preferences, availability of living donors, failure to complete evaluations, and comorbid illnesses [27]. Epstein et al. examined data from five US states and reported that among patients considered clinically appropriate for transplants, African-Americans were less likely than Whites to be referred for transplant evaluations [15]. Lower rates of preemptive LDKT referrals for racial–ethnic minority patients, which result in higher rates of dialysis initiation, might also contribute to higher rates of HLA sensitization and higher burden of medical complications for minorities that impede successful LDKT [70]. Kinchen et al. conducted a national study and found that late evaluations by a nephrologist were associated with greater burden and severity of chronic illnesses and were more common among African-American men than White men [71]. Reduced health care access, including poor availability or utilization of routine follow-up medical care and less health insurance coverage may also contribute to suboptimal long-term clinical outcomes for minority patients and living donors who receive LDKT.

Population and Community-Related Barriers

Population and community-level barriers, such as suboptimal education and poor awareness about the need for living donors, neighborhood resource deprivation, and high rates of chronic illnesses within minority families and social networks also contribute to disparities in LDKT. Suboptimal quality of educational information about LDKT and lack of decision support regarding LDKT as a treatment option may lead to less awareness about the benefits of and need for LDKT within minority communities. Alvaro et al. noted that Hispanic patients reported lack of knowledge about living donation as a barrier to identifying potential donors within their networks and communities [37]. In addition, because a majority of LDKT recipients receive kidneys donated by relatives or nonrelatives emerging from recipients' close social networks, 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. Lei et al. reported familial clustering of kidney disease within a population-based study of patients with kidney disease [47]. A study by Gaylin et al. showed that co-morbid medical conditions, such as cardiovascular disease and obesity (which are highly prevalent among US racial–ethnic minorities) were associated with lower transplant rates [72].

As evidenced by disproportionately lower kidney transplant rates in areas with higher degrees of poverty, patients and potential donors within minority populations may encounter more geographic and socioeconomic barriers to completing transplant workup. Volkova et al. found that neighborhood poverty was strongly associated with ESRD incidence, and increasing neighborhood poverty was associated with a greater disparity in renal disease rates between African-Americans and Whites [48]. Racial–ethnic disparities in community resource allocation and chronic disease burden may also contribute to racial–ethnic differences in kidney transplant rates. Stolzmann et al. found that lower community income and education levels were associated with lower likelihood of receiving transplants [73]. Within a study of United States Renal Data System (USRDS) and US census data, Hall et al. demonstrated that high levels of neighborhood poverty were associated with lower transplant rates among Asians and Pacific Islanders compared with Whites, and the degree of disparity worsened as rates of neighborhood poverty worsened [74].

Emerging research suggests lower health literacy rates within racial–ethnic minority populations may also serve as an important barrier in referral for and completion of transplant evaluations. Grubbs et al. found that inadequate health literacy among hemodialysis patients was associated with lower rates of referral for transplant evaluations [75]. It is postulated that health care providers may be less willing to refer patients with inadequate health literacy due to concerns about patients' inability to complete required steps necessary for transplanted graft survival [75]. Minimal availability and use of language and health literacy-appropriate educational resources about LDKT may contribute to minorities' higher rates of incomplete LDKT workups.

Emerging Strategies to Reduce Barriers to Living Donation

A number of promising initiatives have been recently implemented that could address some of the barriers to LDKT highlighted within this chapter [53] (Table 23.1). Current initiatives include home-based patient and family interventions, culturally sensitive educational and behavioral interventions for patients and families, standardized transplant training for non-transplant health care professionals, increased community awareness about the need for LDKT, and population-based screening programs to detect ESRD and associated risk factors [53]. A number of additional behavioral and clinical interventions have also been implemented to address barriers to completion of the LDKT process. Recent initiatives, targeted at patients and potential donors, health care providers and the health system, and population and community factors include:

Targeting Patients and Potential Donors

- Home, community, and clinic-based LDKT educational programs [76, 77].
- Involvement of patients' extended social networks in educational efforts [78, 79].
- Culturally sensitive preemptive transplant education and behavioral programs [80].

Targeting Health Care Providers and Systems

- Standardized LDKT training for non-transplant health care professionals.
- Paired kidney donation, HLA desensitization, and ABO-incompatible programs to overcome immunological barriers [81].

Table 23.1 Promising initiatives to address barriers to living kidney donation for racial–ethnic minorities [53]

	Donor identification initiatives	Transplant evaluation initiatives	Kidney transplant initiatives	Posttransplant initiatives
Recipient–donor initiatives	Culturally sensitive home and community-based education Programs to educate and engage patients' families and social networks	Financial counseling to address insurance and economic concerns	Educational/behavioral interventions to improve preemptive transplant education	Cultural, literacy, and language appropriate efforts to support patient self-care
Health care provider initiatives	Enhanced provider-patient/family LDKT education Cultural competency and racial diversity of health care providers	Educational support from heterogeneous team of health professionals	Improved health care access and continuity of care	Long-term medical follow-up for living donors Pharmacist-led counseling about medication therapy and adherence
Health system initiatives	Standardized transplant education and training for non-transplant medical professionals	Partnerships with non-health care professionals to enhance social support	Paired kidney exchange programs HLA desensitization and ABO incompatible programs	Comprehensive tracking and health-related monitoring of living donors
Population-community initiatives	Community-based partnerships to promote awareness and trust in minority communities Increased availability of healthy foods, safe physical activity space, and community health screenings	Satellite outreach transplant centers to address potential geographic barriers and enhance rates of transplant referral in rural areas	Federal and state policies to support living donors	Expanded medication coverage and access to primary health care Policies to ensure future insurance eligibility for living donors

LDKT living donor kidney transplantation, *HLA* human leukocyte antigen

Targeting Populations and Communities

- Increased availability of fresh, nutritious foods and access to safe public spaces for exercise and recreation [82].
- Increased community awareness and population-based screening programs for kidney disease and related risk factors (e.g., hypertension and diabetes) [83].
- Initiatives to bring satellite transplant clinics to rural areas to address geographic barriers.

However, many of these initiatives are relatively new. Thus, evidence of long-term effectiveness and optimal methods for implementing and disseminating the interventions are not yet clear. Continued work is needed to enhance existing initiatives and to inform the development of future interventions to overcome racial–ethnic disparities in LDKT.

Policy Initiatives to Reduce Barriers to Living Donation

Over the past decade, a number of federal and state policies have been enacted to provide support for living donors, ranging from paid or unpaid leave and from work to tax benefits for living donors [84]. The National Organ Donor Leave Act of 1999 provides additional leave time from work for living donors who are federal employees [85]. The passage of the 2004 Organ Donation and Recovery Improvement Act authorizes $ 25 million in new resources for efforts to increase donation, including establishment of the National Living Donor Assistance Program, which provides grants for reimbursement of travel and subsistence expenses and incidental nonmedical expenses incurred by low-income individuals undergoing clinical evaluation for living kidney donation [86]. The Medicare Improvements for Patients and Providers Act of 2008 aims to enhance timely provider–patient LDKT education and decision support for pre-ESRD patients. The Medicare National Transplant Education Quality Improvement Initiative, which links dialysis facility quality measures to reimbursement, is a system-level policy intervention designed to improve rates of transplant education within in-center hemodialysis facilities.

There are also a number of proposed policies, such as the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2013 (H.R. 1428, 113th) [87], which aims to amend Title 18 of the Social Security Act to terminate the 36-month limit of immunosuppressive drug coverage for transplant recipients. Additionally, the Kidney Care Quality and Improvement Act of 2005 (H.R. 1298, 109th) [88] and the Kidney Care Quality and Education Act of 2007 (S. 691, 110th) [89] both include provisions for improving the benefits of the Medicare Program for beneficiaries with kidney disease, such as increased kidney disease patient education and public awareness.

Implications and Future Directions for Living Donor Advocacy

In conclusion, racial–ethnic disparities in the prevalence of ESRD are stark, and unequal rates of transplants among minorities compared to Whites exacerbate health inequities. Barriers to kidney transplants exist at multiple levels, and interventions are slowly emerging to address these barriers. Policy initiatives to overcome some barriers exist, but have not yet demonstrated effectiveness in narrowing racial–ethnic disparities in access to LDKT. To further support LDKT and eliminate disparities in LDKT, broad dissemination of successful interventions targeting patient, physician, and health system barriers is needed. Examination of existing policies and ways in which policies might be tailored or expanded to further encourage LDKT may also be warranted. Finally, sustained partnerships among health care professionals, policy makers, patient/donor advocacy groups, and leaders within minority communities may support efforts to mitigate disparities in LDKT for racial–ethnic minorities.

Acknowledgments This work was supported in part by the National Heart, Lung, and Blood Institute (5T32HL007180) and the National Institute of Diabetes and Digestive and Kidney Diseases (1R01DK079682 and 1R01DK098759).

References

1. U.S. Renal Data System, USRDS 2011 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2011.
2. American Association of Kidney Patients. AAKP Reviews 30 Years of the Medicare ESRD Program. http://www.aakp.org/aakp-library/30-years-medicare-esrd-program. Accessed Apr 2012.
3. Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, et al. Prevalence of chronic kidney disease in the United States. JAMA. 2007;298:2038–47.
4. Agency for Health care Research and Quality. 2011 National Health care Disparities Report. Rockville, MD: U.S. Department of Health and Human Services, Agency for Health care Research and Quality; March 2012. AHRQ Pub. No. 12–0006.
5. Young CJ, Gaston RS. African Americans and renal transplantation: Disproportionate need, limited access, and impaired outcomes. Am J Med Sci. 2002;323:94–9.
6. United States Census Bureau. Population Estimates. http://www.census.gov/popest/estimates.php. Accessed Apr 2012.
7. Martins D, Tareen N, Norris KC. The epidemiology of end-stage renal disease among African Americans. Am J Med Sci. 2002;323:65–71.
8. Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LYC, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. N Engl J Med. 1999;341(23):1725–30.
9. Purnell TS, Auguste P, Crews DC, Lamprea-Montealegre J, Olufade T, Greer RC, et al. Comparison of life participation activities among adults treated by hemodialysis, peritoneal dialysis, and kidney transplantation: A systematic review. Am J Kidney Dis. 2013 May [Epub ahead of print].

10. Ichikawa Y, Fujisawa M, Hirose E, Kageyama T, Miyamoto Y, Sakai Y, et al. Quality of life in kidney transplant patients. Transplant Proc. 2000;32(7):1815–6.
11. Manninen DL, Evans RW, Dugan MK. Work disability, functional limitations, and the health status of kidney transplantation recipients post-transplant (Los Angeles: UCLA Tissue Typing Laboratory). Clinical Transplants. 1991;2:193–203.
12. Jofre R, Lopez-Gomez JM, Moreno F, Sanz-Guajardo D, Valderrabano F. Changes in quality of life after renal transplantation. Am J Kidney Dis. 1998;32(1):93–100.
13. Eggers PW. Racial differences in access to kidney transplantation. Health Care Financing Rev. 1995;17(2):89–103.
14. Delano BG, Macey L, Friedman EA. Gender and racial disparity in peritoneal dialysis patients undergoing kidney transplantation. Am Soc Art Int Org. 1997;43:M861–4.
15. Epstein AM, Ayanian JZ, Keogh JH, Noonan SJ, Armistead N, Cleary PD, et al. Racial disparities in access to renal transplantation—clinically appropriate or due to underuse or overuse? N Engl J Med. 2000;343:1537–44.
16. Sequist TD, Narva AS, Stiles SK, Karp SK, Cass A, Ayanian JZ. Access to renal transplantation among American Indians and Hispanics. Am J Kidney Dis. 2004;44:344–52.
17. Alexander GC, Sehgal AR. Barriers to cadaveric renal transplantation among blacks, women, and the poor. JAMA. 1998;280(13):1148–52.
18. Isaacs RB, Lobo PI, Nock SL, Hanson JA, Ojo AO, Pruett TL. Racial disparities in access to simultaneous pancreas-kidney transplantation in the United States. Am J Kidney Dis. 2000;36:526–33.
19. Ojo A, Port FK. Influence of race and gender on related donor renal transplantation rates. Am J Kidney Dis. 1993;22:835–41.
20. Alexander GC, Sehgal AR. Why hemodialysis patients fail to complete the transplantation process. Am J Kidney Dis. 2001;37(2):321–8.
21. Ayanian JZ, Cleary PD, Weissman JS, Epstein AM. The effect of patients' preferences on racial differences in access to renal transplantation. N Engl J Med. 1999;341(22):1661–9.
22. Gaston RS, Ayres I, Dooley LG, Diethelm AG. Racial equity 2 renal transplantation. The disparate impact of HLA-based allocation. JAMA. 1993;270(11):1352–6.
23. Young CJ, Gaston RS. Renal transplantation in black Americans. N Engl J Med. 2000;343(21):1545–52.
24. Kasiske BL, London W, Ellison MD. Race and socioeconomic factors influencing early placement on the kidney transplant waiting list. J Am Soc Nephrol. 1998;9:2142–7.
25. Soucie JM, Neylan JF, McClellan W. Race and sex differences in the identification of candidates for renal transplantation. Am J Kidney Dis. 1992;19:414–9.
26. Navaneethan SD, Singh S. A systematic review of barriers in access to renal transplantation among African Americans in the United States. Clin Transplant. 2006;20:769–77.
27. Ayanian JZ, Cleary PD, Keogh JH, Noonan SJ, David-Kasdan JA, Epstein AM. Physicians' beliefs about racial differences in referral for renal transplantation. Am J Kidney Dis. 2004;43:350–7.
28. Gordon EJ. Patients' decisions for treatment of end-stage renal disease and their implications for access to transplantation. Soc Sci Med. 2001;53:971–87.
29. Hicks LS, Cleary PD, Epstein AM, Ayanian JZ. Differences in health-related quality of life and treatment preferences among black and White patients with end-stage renal disease. Qual Life Res. 2004;13:1129–37.
30. Hall YN, Rodriguez RA, Boyko EJ, Chertow GM, O'Hare AM. Characteristics of uninsured Americans with chronic kidney disease. J Gen Intern Med. 2009;24(3):917–22.
31. Cecka M. Clinical outcome 2 renal transplantation. Factors influencing patient and graft survival. Surg Clin North Am. 1998;78:133–48.
32. Nanovic L, Kaplan B. The advantage of live-donor kidney transplantation in older recipients. Renal Web and Nature Clinical Practice Nephrology. 2008;5:18–19.
33. Purnell TS, Xu P, Leca N, Hall YN. Racial differences in determinants of live donor kidney transplantation in the United States. Am J Transplant. 2013 June;13(6):1557–65.

34. Gore JL, Danovitch GM, Litwin MS, Pham PT, Singer JS. Disparities in the utilization of live donor kidney transplantation. Am J Transplant. 2009;9:1124–33.
35. United Network for Organ Sharing. Organ Procurement and Transplantation Network Data: Kidney Transplants in the US: 1988–2013. http://optn.transplant.hrsa.gov/latestData/rptData.asp. Accessed May 2013.
36. Weng FL, Reese PP, Mulgaonkar S, Patel AM. Barriers to living donor kidney transplantation among black or older transplant candidates. Clin J Am Soc Nephrol. 2010;5(12):2338–47.
37. Alvaro EM, Siegel JT, Turcotte D, Lisha N, Crano WD, Dominick A. Living kidney donation among Hispanics: a qualitative examination of barriers and opportunities. Prog Transplant. 2008;18(4):243–50.
38. Boulware LE, Ratner LE, Sosa JA, Cooper LA, LaVeist TA, Powe NR. Determinants of willingness to donate living related and cadaveric organs: identifying opportunities for intervention. Transplant. 2002;73:1683–91.
39. Robinson DHZ, Borba CPC, Thompson NJ, Perryman JP, Arriola KRJ. Correlates of support for living donation among African American adults. Prog Transplant. 2009;19:244–51.
40. Pradel FG, Suwannaprom P, Mullins CD, Sadler J, Bartlett ST. Haemodialysis patients' readiness to pursue live donor kidney transplantations. Nephrol Dial Transplant. 2009;24:1298–305.
41. Boulware LE, Hill-Briggs F, Kraus ES, Melancon JK, Senga M, Evans KE, et al. Identifying and addressing barriers to African American and non-African American families' discussions about preemptive living related kidney transplantation. Prog Transplant. 2011;21:97–105.
42. Waterman AD, Stanley SL, Covelli T, Hazel E, Hong BA, Brennan DC. Living donation decision making: recipients' concerns and educational needs. Prog Transplant. 2006;16:17–23.
43. Lunsford SL, Simpson KS, Chavin KD, Hildebrand LG, Miles LG, Shilling LM, et al. Racial differences in coping with the need for kidney transplantation and willingness to ask for live organ donation. Am J Kidney Dis. 2006;47:324–31.
44. Lunsford SL, Shilling LM, Chavin KD, Martin MS, Miles LG, Norman ML, et al. Racial differences in the living kidney donation experience and implications for education. Prog Transplant. 2007;17:234–40.
45. Shilling LM, Norman ML, Chavin KD, Hildebrand LG, Hildebrand LG, Lunsford SL, Martin MS, et al. Health care professionals' perceptions of the barriers to living donor kidney transplantation among African Americans. J Natl Med Assoc. 2006;98(6):834–9.
46. Boulware LE, Meoni LA, Fink NE, Parekh RS, Kao WH, Klag MJ, et al. Preferences, knowledge, communication, and patient-physician discussion of living kidney transplantation in African American families. Am J Transplant. 2005;5(6):1503–12.
47. Lei HH, Perneger TV, Klag MJ, Whelton PK, Coresh J. Familial aggregation of renal disease in a population-based case-control study. J Am Soc Nephrol. 1998;9:1270–6.
48. Volkova N, McClellan W, Klein M, Flanders D, Kleinbaum D, Soucie JM, et al. Neighborhood poverty and racial differences in ESRD incidence. J Am Soc Nephrol. 2008;19:356–64.
49. Reeves-Daniel A, Adams PL, Assimos D, Westcott C, Alcorn SG, Rogers J, et al. Impact of race and gender on live kidney donation. Clin Transplant. 2009;23:39–46.
50. Tankersely MR, Gaston RS, Curtis JJ, Julian BA, Deierhoi MH, Rhynes VK, et al. The living donor process in kidney transplantation: influence of race and comorbidity. Transplant Proc. 1997;29:3722–3.
51. Lunsford SL, Simpson KS, Chavin KD, Menching KJ, Miles LG, Shilling LM, et al. Racial disparities in living kidney donation: is there a lack of willing donors or an excess of medically unsuitable candidates? Transplantation. 2006;82:876–81.
52. Clark CR, Hicks LS, Keogh JH, Epstein AM, Ayanian JZ. Promoting access to renal transplantation: the role of social support networks in completing pre-transplant evaluations. J Gen Intern Med. 2008;23:1187–93.
53. Purnell TS, Hall YN, Boulware LE. Understanding and overcoming barriers to living kidney donation among racial and ethnic minorities in the United States. Adv Chronic Kid Dis. 2012;19(4):244–51.

54. Burke G, Esquenazi V, Gharagozloo H, Roth D, Strauss J, Kyriakides G, et al. Long-term results of kidney transplantation at the University of Miami. Clin Transpl. 1989;215–228.
55. Douzdijan V, Thacker LR, Blanton JW. Effect of race on outcome following kidney and kidney-pancreas transplantation in type I diabetes: the South-Eastern Organ Procurement Foundation experience. Clin Transplant. 1997;11:470–5.
56. Foley DP, Patton PR, Meier-Kriesche HU, Li Q, Shenkman B, Fujita S, et al. Long-term outcomes of kidney transplantation in recipients 60 years of age and older at the University of Florida. Clin Transplant. 2005; 101–9.
57. Purnell TS, Powe NR, Troll M, Wang NY, Haywood C, LaVeist TA, et al. Measuring and explaining racial and ethnic differences in willingness to donate live kidneys in the United States. Clin Transplant. [Epub ahead of print]
58. Clarke KS, Klarenbach S, Vlaicu S, Yang RC, Garg AX. The direct and indirect economic costs incurred by living kidney donors-a systematic review. Nephrol Dial Transplant. 2006;21:1952–60.
59. Jacobs C, Thomas C. Financial considerations in living organ donation. Prog Transplant. 2003;13:130–6.
60. Wolters HH, Heidenreich S, Senniger N. Living donor kidney transplantation: chance for the recipient—financial risk for the donor? Transplant Proc. 2003;35:2091–2.
61. United Network for Organ Sharing. Costs related to living donation. http://www.optn.org/about/donation/livingDonation.asp#costs. Accessed Apr 2012.
62. Johnson EM, Anderson JK, Jacobs C, Suh G, Humar A, Suhr BD, et al. Long-term follow-up of living kidney donors: quality of life after donation. Transplantation. 1999;67:717–2.
63. Spital A, Jacobs C. Life insurance for kidney donors: another update. Transplantation. 2002;74(7):972–3.
64. Gibney EM, King AL, Maluf DG, Garg AX, Parikh CR. Living kidney donors requiring transplantation: focus on African Americans. Transplantation. 2007;84:647–9.
65. Gibney EM, Parikh CR, Garg AX. Age, gender, race, and associations with kidney following living kidney donation. Transplant Proc. 2008;40:1337–40.
66. Doshi M, Garg AX, Gibney E, Parikh C. Race and renal function early after live kidney donation: an analysis of the United States Organ Procurement and Transplantation Network Database. Clin Transplant. 2010;24:E153–57.
67. Lentine KL, Schnitzler MA, Xiao H, Saab G, Salvalaggio PR, Axelrod D, et al. Racial variation in medical outcomes among living kidney donors. N Engl J Med. 2010;363(8):724–32.
68. Nogueira JM, Weir MR, Jacobs S, Haririan A, Breault D, Klassen D, et al. A study of renal outcomes in African American living kidney donors. Transplantation. 2009;88:1371–6.
69. Segev DL, Muzaale AD, Caffo BS, Mehta SH, Singer AL, Taranto SE, et al. Perioperative mortality and long-term survival following live kidney donation. JAMA. 2010;303(10):959–66.
70. Kasiske BL, Snyder JJ, Matas AJ, Ellison MD, Gill JS, Kausz AT. Preemptive kidney transplantation: The advantage and the advantaged. J Am Soc Nephrol. 2002;13:1358–64.
71. Kinchen KS, Sadler J, Fink N, Brookmeyer R, Klag MJ, Levey AS, Powe NR. The timing of specialist evaluation in chronic kidney disease and mortality. Ann Intern Med. 2002;137:479–86.
72. Gaylin DS, Held PJ, Port FK, Hunsicker LG, Wolfe RA, Kahan BD, et al. The impact of comorbid sociodemographic factors on access to renal transplantation. JAMA. 1993;269:603–8.
73. Stolzmann KL, Bautista LE, Gangnon RE, McElroy JA, Becker BN, Remington PL. Trends in kidney transplantation rates and disparities. J Natl Med Assoc. 2007;99(8):923–32.
74. Hall YN, O'Hare AM, Young BA, Boyko EJ, Chertow GM. Neighborhood poverty and kidney transplantation among US Asians and Pacific Islanders with end-stage renal disease. Am J Transplant. 2008;8:2402–9.
75. Grubbs V, Gregorich SE, Perez-Stable EJ, Hsu CY. Health literacy and access to kidney transplantation. Clin J Am Soc Nephrol. 2009;4:195–200.

76. Rodrigue JR, Cornell DL, Kaplan B, Howard RJ. A randomized trial of a home-based educational approach to increase live donor kidney transplantation: effects in blacks and whites. Am J Kidney Dis. 2008;51:663–70.
77. Waterman AD, Hyland SS, Goalby C, Robbins M, Dinkel K. Improving transplant education in the dialysis setting: the "explore transplant" initiative. Dialysis Transplantation. 2010;39(6):236–41.
78. Clark CR, Hicks LS, Keogh JH, Epstein AM, Ayanian JZ. Promoting access to renal transplantation: the role of social support networks in completing pre-transplant evaluations. J Gen Intern Med. 2008;23:1187–93.
79. Garonzik-Wang JM, Berger JC, Ros RL, Kucirka LM, Deshpande NA, Boyarsky BJ, et al. Live donor champion: finding live kidney donors by separating the advocate from the patient. Transplantation. 2012;93(11):1147–50.
80. Boulware LE, Hill-Briggs F, Kraus ES, Melancon JK, Falcone B, Ephraim PL, et al. Effectiveness of educational and social worker interventions to improve pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. Am J Kidney Dis. 2013;61(3):476–86.
81. Warren DS, Montgomery RA. Incompatible kidney transplantation: lessons from a decade of desensitization and paired kidney exchange. Immunol Res. 2010;47(1–3):257–64.
82. Sallis JF, Bauman A, Pratt M. Environmental and policy interventions to promote physical activity. Am J Prev Med. 1998;15(4):379–97.
83. National Kidney Foundation. The Kidney Early Evaluation Program (KEEP). http://www.kidney.org/news/keep/KEEPabout.cfm. Accessed May 2013.
84. National Conference of State Legislatures. State Leave Laws Related to Medical Donors. http://www.ncsl.org/programs/employ/Leave-medicaldonors.htm. Accessed Apr 2012.
85. United States Public Laws. Organ Donor Leave Act. 5 USC 9601: H.R. 457. http://thomas.loc.gov/cgi-bin/query/z?c106:H.R.457.
86. United States Public Laws. Organ Donation and Recovery Improvement Act. 42 USC 201: 108 H.R. 3926. http://www.govtrack.us/congress/bills/108/hr3926c.
87. Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2013. H.R. 1428, 113th. http://www.govtrack.us/congress/bills/113/hr1428/text.
88. Kidney Care Quality and Improvement Act of 2005. H.R. 1298, 109th. http://www.govtrack.us/congress/bills/109/hr1298.
89. Kidney Care Quality and Education Act of 2007. S. 691, 110th. http://www.govtrack.us/congress/bills/110/s691.