

Assessment of Barriers to Donation for Potential Black Kidney Donors



Jessica Kearney¹, Priscilla Smith¹, Rob Elias¹ and Kate Bramham^{1,2}

¹King's Kidney Care, Kings College Hospital NHS Foundation Trust, London, UK; and ²Department of Women and Children's Health, King's College London, London, UK

Correspondence: Kate Bramham, Department of Women and Children's Health, School of Life Course Sciences, Faculty of Life Sciences and Medicine, King's College London, Weston Education Centre, 10 Cutcombe Road, London, SE5 9RJ, UK. E-mail: kate.bramham@kcl.ac.uk

Received 23 August 2020; revised 20 October 2020; accepted 10 November 2020; published online 20 November 2020

Kidney Int Rep (2021) 6, 493–495; <https://doi.org/10.1016/j.ekir.2020.11.008>

© 2020 Published by Elsevier, Inc., on behalf of the International Society of Nephrology. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

KEYWORDS: Chronic Kidney Disease; Transplantation; Hypertension; Ethnicity; APOL1; Genotype

© 2020 Published by Elsevier, Inc., on behalf of the International Society of Nephrology. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

People of Black ethnicity are more likely to develop end-stage kidney disease (ESKD)¹ but are less likely to be preemptively listed for transplantation in the United Kingdom,² and on average waiting times are 327 days longer compared with 573 days for White patients.³ Living donor kidney transplantation is the gold standard treatment for ESKD.⁴ From 2019 to 2020, 3488 kidney transplants were performed in the United Kingdom and 982 (28%) were from living donors.³ In the same period, 12% of patients listed for kidney transplantation in the United Kingdom were of Black ethnicity, but only 26 (3%) of living kidney donors were Black compared with 846 (86%) White donors.³ We sought to understand factors contributing to low numbers of Black living donors in our unit, which provides dialysis for the highest proportion of patients of Black ethnicity in the United Kingdom.

We performed a retrospective assessment of all potential kidney donors who had attended an initial meeting with a nurse specialist or consultant over 6 years (January 2014–July 2020) in a London nontransplant teaching hospital. Demographics including self-reported ethnicity and medical history were extracted from electronic records. An initial screening questionnaire, medical examination, baseline bloods, and proteinuria assessment were performed. Donor investigations were undertaken according to British Renal Society Guidelines.⁴ Since 2015, Apolipoprotein L1 genotyping was also performed for potential donors of self-reported Black ethnicity who were deemed suitable to proceed after initial investigations. Genetic counseling was provided by a consultant nephrologist before testing. The

decision not to proceed to transplantation was made by a multidisciplinary team including doctors and nurses, in keeping with British Renal Society Guidelines, and if necessary a second opinion was sought.

Reasons for not proceeding to donation were categorized as donor or recipient-related or other. Recipient-related reasons included being medically unfit or patient choice not to proceed. Donor-related factors were categorized as medical or social factors. Medical reasons included body mass index, impaired renal function, hypertension, raised HbA1C, anatomic anomalies, proteinuria, APOL1 genetics, and other (infrequently listed reasons). The factors were categorized as social if the donor's social circumstances (e.g., if they were unable to have someone care for them after the procedure) or preferences meant they decided against transplantation. Differences between ethnic groups were compared by Fisher's exact testing.

At time of data collection, 36% of patients on our transplant waiting list were of Black ethnicity. Demographics of 340 potential kidney donors are shown in Table 1. Black potential donors were less likely to proceed than White ($P = 0.001$) or "other" ethnicities ($P = 0.09$). Black potential donors were much more likely to have donor-related factors precluding donation than White donors (73.3% vs. 48.9%; $P = 0.001$). Hypertension was the most frequent medical reason for Black potential donors being excluded and was significantly more common than for both White potential donors ($P = 0.002$) and "other" ethnicities ($P = 0.04$). However, the proportion of potential donors who were not medically fit due to high body mass index or

Table 1. Potential donor characteristics and reasons for not proceeding to transplantation

Characteristic	Black	White	Other
Total number, <i>n</i> (% of all)	82 (24.12)	190 (55.8)	68 (20.0)
Average age, \bar{y} (SD)	43.7 (11.2)	47.9 (12.9)	45.2 (12.5)
Gender, % male	46.30	41.60	48.50
Proceeded to transplant, <i>n</i> (% of group)	7 (8.5) ^{a,b}	49 (25.8) ^a	13 (19.1) ^b
Did not proceed, <i>n</i> (% of group)	75 (91.5)	141 (74.2)	55 (80.9)
Reason for not proceeding			
Donor reason, <i>n</i> (% of those not proceeding)	55 (73.3) ^c	71 (50.4) ^c	33 (60.0)
Recipient reason, <i>n</i> (% of those not proceeding)	6 (8.0)	24 (17.0)	7 (12.7)
Other, <i>n</i> (% of those not proceeding)	14 (18.7)	46 (32.6)	15 (27.3)
Donor reason, <i>n</i> (%)			
Medical	41 (69.6)	58 (84)	24 (72.7)
Social	14 (30.4)	11 (15.5)	9 (27.3)
Medical reason, <i>n</i> (%)			
High BMI	11 (26.8)	17 (29.3)	8 (33)
eGFR too low	8 (19.5)	13 (21.7)	5 (20.8)
Hypertension	13 (31.7) ^{d,e}	4 (6.7) ^d	2 (8.3) ^e
Elevated HbA1C/Impaired Fasting Glucose	5 (12.1)	2 (3.3)	1 (4.2)
Anatomical	0 (0)	10 (16.7)	4 (16.7)
Proteinuria	4 (9.75)	2 (3.45)	2 (8.33)
APOL1	7 (17.1)	N/A	N/A
Other	5 (12.2)	15 (25)	3 (12.5)
More than one reason listed	10	6	2

BMI, body mass index; eGFR, estimated glomerular filtration rate; HbA1C, glycated hemoglobin, NA, not available.

More white donors and those from other ethnicities proceeded to transplantation versus black donors ($P = 0.0018$ and $P = 0.0218$ respectively). Of those that did not proceed more often in the black group it was due to reasons with the donor versus the white group ($P = 0.0021$). Hypertension was listed more frequently as the reason not to donate in black donors compared with white ($P = 0.0005$)

^a $P = 0.001$.

^b $P = 0.09$.

^c $P = 0.001$.

^d $P \leq 0.002$.

^e $P = 0.04$.

Where more than 1 medical reason was listed, each reason was counted. Percentages are presented as proportion of ethnic group.

low estimated glomerular filtration rate were comparable between donor ethnicities.

Despite the high proportion of Black patients on our transplant waiting list, lower numbers of potential kidney donors were Black compared with White ethnicities and only approximately 1 in 12 Black potential donors proceeded to donate. An important novel finding of this study was that additional medical barriers, predominantly due to preexisting hypertension but also APOL1 high-risk genotypes precluded donation for potential Black donors.

In the United Kingdom between 2015 and 2020, only 111 living kidney donors were Black, and over the same period, the proportion of Black patients on the transplant waiting list has increased from 11.2 to 11.6%.^{S1} Studies from the United States have reported that fewer Black people are willing to volunteer for kidney donation due to financial reasons, lack of medical trust, lack of awareness, and reluctance to ask family members,⁵ but confirmation of these factors in the United Kingdom is needed.

Estimated risk of ESKD at 15 years after donation is 74.7 and 22.7 per 10,000 in Black and White donors, respectively.⁶ Mechanism of progression to ESKD in Black donors is unclear; hypertension and socioeconomic factors have been proposed, and it is recommended that potential Black donors are counseled about the increased risk of ESKD after donation.⁴

More recently, genetic factors have also been associated with risk of ESKD in Black patients. In our practice, 7 of 21 potential donors who had genetic testing were excluded due to the presence of high-risk APOL1 genotypes. In a UK cohort of 20 potential Black donors, 30% were excluded due to the presence of high-risk APOL1 genotypes.⁷ Currently there is no consensus about screening for APOL1 genotypes in Black potential kidney donors and The APOL1 Long-term Kidney Transplantation Outcomes Network (APOLLO) study (NCT03615235) findings are awaited; however, concerns about a more rapid fall in estimated glomerular filtration rate post-donation in donors with 2 APOL1 risk alleles⁸ and worse outcomes for recipients of grafts for high-risk APOL1 donors⁹ have led to many centers using APOL1 genotype testing as a routine investigation for Black potential kidney donors.^{S2}

Although education, including by peer educators, has been suggested as an approach to augment the number of Black donors, immediate solutions to alter genetic and other medical factors that may prohibit donation are needed. Targeting younger Black donors who are less likely to have comorbidities may be beneficial, but this approach is associated with other complex ethical concerns, including higher lifetime risk of progression to ESKD.⁹

Our findings confirm that Black potential donors are few, and only a small proportion proceed to donate due to concerns about their health. Seeking to identify and encourage potential Black donors without comorbidities may increase the proportion of people able to proceed. But ambiguity about their lifetime risk of progression to ESKD, even with APOL1 genotyping, may still prove a barrier.

DISCLOSURES

All the authors declared no competing interests. The results presented in this paper have not been published previously in whole or part, except in abstract format.

AUTHOR CONTRIBUTIONS

Research idea and study design: RE; data acquisition: JK, PS; data analysis/interpretation: JK, PS, KB; statistical analysis: JK, PS, KB.

SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

[Supplementary References.](#)

REFERENCES

1. Caskey F, Dreyer G. Kidney health inequalities in the United Kingdom: reflecting on the past, reducing in the future 2018. Available at: https://kidneyresearchuk.org/wp-content/uploads/2019/09/Health_Inequalities_lay_report_FINAL_WEB_20190311.pdf. Accessed July 1, 2020.
2. Pruthi R, Robb ML, Oniscu GC, et al. Inequity in access to transplantation in the United Kingdom. *Clin J Am Soc Nephrol*. 2020;15:830–842.
3. NHS Blood and Transplant. Organ donation and transplantation: Activity Report 2019-2020. Available at: <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/19220/activity-report-2019-2020.pdf>. Accessed July 1, 2020.
4. Andrews PA, Burnapp L. British Transplantation Society/ Renal Association UK Guidelines for Living Donor Kidney Transplantation 2018. Available at: https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf. Accessed July 1, 2020.
5. Purnell TS, Powe NR, Troll MU, et al. Measuring and explaining racial and ethnic differences in willingness to donate live kidneys in the United States. *Clin Transplant*. 2013;27:673–683.
6. Muzaale AD, Massie AB, Wang M, et al. Risk of end-stage renal disease following live kidney donation. *JAMA*. 2014;311:579–586.
7. Dick J, Asgari E, Chowdhury P, et al. Incorporating apolipoprotein L1 testing into evaluation of potential living kidney donors: a single-centre experience. *Clin Kidney J*. 2019;12:574–575.
8. Doshi MD, Ortigosa-Goggins M, Garg AX, et al. APOL1 genotype and renal function of black living donors. *J Am Soc Nephrol*. 2018;29:1309–1316.
9. Freedman BI, Pastan SO, Israni AK, et al. APOL1 genotype and kidney transplantation outcomes from deceased African American donors. *Transplantation*. 2016;100:194–202.