Perceived Susceptibility to Chronic Kidney Disease and Hypertension Self-Management among Black and White Live Kidney Donors

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Background: Despite the societal benefits of live kidney donation, Black donors may be more likely than White donors to develop hypertension (HTN) and chronic kidney disease after donation. Among live kidney donors diagnosed with post-donation HTN, little is known about potential racial/ethnic differences in HTN self-care behaviors and perceived susceptibility to developing kidney disease.

Methods: We ascertained electronic medical records and phone survey data from live donors enrolled in the multi-center Wellness and Health Outcomes of LivE Donors (WHOLE-Donor) Hypertension Care Study between May 2013 and April 2020. Using multivariable logistic regression models performed January through June 2021, we examined potential associations of donor race/ethnicity with perceived susceptibility to kidney disease and self-care behaviors (ie, Behavioral Risk Factor Surveillance System measure assessing self-reported actions to control high blood pressure).

Results: The study included 318 US-based live kidney donors who developed post-donation HTN (57.6% female; 78.9% White; 18.6% Black; and mean age 46.7 years at donation). Black donors were equally as likely as White donors to report being moderately or strongly concerned about developing kidney disease (adjusted odds ratio, aOR: 1.27, 95%CI: .66, 2.14, P=.57). Donors with diabetes were more likely than those without diabetes (aOR: 2.43, 95%CI: 1.03, 5.01, P=.04), while donors aged >50 years were less likely than younger donors (aOR: .39, 95%CI: .18, .85, P=.02) to report being moderately or strongly concerned about kidney disease. Overall, 87% of donors reported taking at least one action to help control blood pressure, with no significant differences by sociodemographic factors.

Conclusions: We found no substantial differences in perceived susceptibility to kidney disease among Black and White donors, despite published evidence that Black donors may experience greater risk of developing kidney disease than White donors. Behavioral interventions to enhance knowledge about future disease risk, attitudes, and self-care strategies among living kidney donors may be beneficial. *Ethn Dis*. 2022;32(2):101-108; doi:10.18865/ed.32.2.101

Keywords: Kidney Disease; Hypertension; Kidney Donors

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Introduction

Live donor kidney transplantation (KT) is associated with longer life expectancy and better quality of life than long-term dialysis treatment or deceased donor KT for clinically suitable patients with kidney failure.[1] As of 2021, there are 90,421 candidates on the US waiting list for KT with a higher proportion of Black (31.4%) and Hispanic (21.3%) candidates than their representation in the general population.[2] In the United States, live donors accounted for approximately 33% of all KTs from 2008-2017.[3] National data reported by race/ethnicity indicated that 70.7% of live kidney donors in 2019 were White, as compared with 8.7% Black and 14.8% Hispanic.[3] Although live kidney donation is generally considered to be a safe procedure, recent evidence suggests that some donors may experience increased risk of developing hyper-

tension (HTN) and associated sequalae.[4-8] For instance, using national pharmacy claims data, Lentine et al[4] reported that by five years post-donation, 17.8% of privately insured donors in the study had filled a prescription for antihypertensive medications (AHM), with Black donors incurring 37% higher likelihood of AHM prescriptions than White donors.

Post-donation HTN has also been associated with proteinuria, decreased glomerular filtration rate, cardiovascular disease, and kidney failure.[5] Within a matched cohort study of 96,217 live kidney donors, Muzaale et al[6] reported that at 15 years post-donation, estimated risk of kidney failure was 74.7 per 10,000 among Black donors, as compared with 23.9 per 10,000 among Black non-donor controls and 22.7 per 10,000 among White donors. A better understanding of attitudinal, behavioral, and clinical care factors associated with development of kidney failure among live kidney donors is needed to prevent or slow progression of kidney disease within live donors who develop post-donation HTN, as well as to alleviate concerns about donation-related health risks that may contribute to transplant disparities.[9,10]

The goal of this study was to examine self-care behaviors and perceived susceptibility to kidney disease among Black and White donors who developed post-donation HTN.

In the general patient population, participation in HTN self-care behaviors has been associated with a lower likelihood of developing kidney disease and other HTN-related sequalae.[11] Attitudinal factors, including perceived susceptibility to kidney disease, may also influence willingness to adhere to needed lifestyle changes (eg, diet, physical activity, smoking cessation) to lower the risk of developing kidney disease, particularly among higher-risk patients (eg, Black adults).[12-14] The Health Belief Model (HBM) proposes that people are most likely to take preventative action if they perceive the threat of a health risk to be serious and if they feel they are personally susceptible.[15] However, little is known about potential racial/ethnic differences in perceived susceptibility to kidney disease and self-care behaviors among live kidney donors. The goal of this study was to examine self-care behaviors and perceived susceptibility to kidney disease among Black and White donors who developed post-donation HTN.

Methods

Study Population

Our study population included adult live kidney donors who participated in the WHOLE-Donor Hypertension Care Study, an ancillary study to the National Institutes of Health–funded WHOLE-Donor (Wellness and Health Outcomes in LivE DONORs) cohort.[7,16] Established in 2011, the WHOLE-Donor cohort is an ongoing multicenter study of adults who donated live kidneys at one of six US-based transplant centers.[7,16] Study investigators invited eligible donors (ie, US-based living kidney donors aged 18–66 years at the time of donation with at least two years of post-donation follow-up data) to participate in the study via telephone and mail recruitment.

The WHOLE DONOR Hypertension ancillary study was conducted to identify attitudinal, behavioral, and sociodemographic factors associated with self-management behaviors, quality of medical care, and long-term health outcomes for adults who donated a kidney and developed hypertension after donation. This study excluded donors known to be living outside the United States and those who did not speak English. Eligible donors were contacted by telephone or mail and invited to participate in the study. Participants consented to sharing their post-donation electronic medical records (EMRs) and completed a survey (Module H) by telephone call. Study data were then obtained from EMRs and surveys. Data collection for this study took place between May 2013 and April 2020; the analysis was carried out between January through June 2021.This study was approved by the Johns Hopkins Institutional Review Board (NA_00044282).

Clinical and Sociodemographic Data Collection

Using structured forms, study investigators abstracted medical diagnoses (eg, hypertension, diabetes,

Table 1. Sociodemographic characteristics of living kidney donors diagnosed with post-donation hypertension, N=318

Characteristics	Overall, n (%)	By Anti-Hypertensive Medication Type					
		Any AHM	Diuretics	ACEi/ARBs	CCBs	BBs	Other AHM
Age group							
18-35 years	54 (16.9)	52 (96.3)	8 (50)	10 (58.8)	7 (41.2)	9 (56.3)	8 (47.1)
36-49 years	135 (42.5)	131 (97.04)	14 (35)	17 (42.5)	19 (47.5)	14 (35)	12 (30)
≥50 years	129 (40.6)	127 (98.5)	25 (43.1)	34 (57.6)	23 (39.7)	23 (38.9)	22 (37.9)
Sex							
Female	183 (57.6)	179 (97.8)	24 (40.7)	28 (47.5)	24 (41.4)	22 (37.29)	21 (35.6)
Male	135 (42.45)	131 (97.04)	32 (58.2)	33 (57.9)	25 (43.9)	24 (42.9)	21 (37.5)
Race/ethnicity							
White	251 (78.9)	246 (98.01)	39 (41.5)	53 (55.8)	38 (40.4)	37 (38.6)	35 (37.2)
Black	59 (18.6)	57 (96.6)	5 (31.3)	7 (41.2)	9 (52.9)	6 (37.5)	6 (35.3)
Other	8 (2.5)	7 (87.5)	3 (75)	1 (25)	2 (50)	3 (75)	1 (25)
Highest level of education							
<College graduate	234 (74.1)	228 (97.4)	39 (46.4)	49 (56.9)	34 (40)	32 (37.7)	35 (41.2)
College graduate or beyond	82 (25.9)	80 (97.6)	8 (28.6)	12 (42.9)	14 (50)	13 (46.4)	6 (21.4)
Health insurance status							
No insurance	5 (1.7)	5 (100)	2 (66.7)	2 (66.7)	2 (66.7)	2 (66.7)	0 (0)
Any Insurance	284 (97.9)	276 (97.2)	41 (41)	55 (52.9)	41 (40.6)	40 (39.6)	37 (36.6)
Marital status							
Single/not married	91 (28.6)	86 (94.5)	9 (32.1)	14 (50)	12 (42.9)	10 (35.7)	4 (14.3)
Married/living with a partner	227 (71.38)	224 (98.7)	38 (44.2)	47 (52.4)	37 (42.5)	36 (41.4)	38 (43.7)
Employment status							
Full-time/part-time	185 (58.4)	178 (96.2)	30 (44.1)	38 (44.4)	25 (36.8)	22 (32.4)	27 (39.1)
Retired	97 (30.6)	96 (98.8)	15 (38.5)	19 (48.7)	19 (48.7)	20 (51.3)	13 (33.3)
Unemployed	35 (11.04)	35 (100)	2 (28.6)	4 (50)	5 (62.5)	4 (50)	2 (28.6)
Diabetes status							
Diabetes	38 (12.5)	259 (97.7)	38 (41.8)	46 (50)	36 (39.1)	36 (39.1)	30 (32.6)
No diabetes	265 (87.5)	36 (94.7)	6 (35.3)	14 (22.2)	9 (52.9)	8 (47.1)	10 (58.8)

Data are n(%)
AHM, antihypertensive medication; ACEi/ARBs, ACE inhibitors/angiotensin II receptor blockers, CCBs, calcium channel blockers, BBs, beta blockers

kidney disease), clinical measures (eg, systolic and diastolic blood pressure readings, anti-hypertensive medications, serum creatinine, estimated glomerular filtration rate, blood glucose) and physician notes from EMRs. Through phone surveys, participants were asked about their sociodemographic information, including race/ethnicity, sex, birthdate, age at donation, marital status, highest level of education completed, and employment status. In addition to EMR data abstractions, participants were asked through the phone survey whether they were diagnosed with hypertension after donation, year of diagnosis, and whether they follow the hypertension treatment plan recommended by their primary care doctors.

Perceived Susceptibility to Kidney Disease Survey Measures

As defined by the HBM, perceived susceptibility refers to beliefs about the likelihood of getting a disease or condition.[15] We used published survey measures by Boulware et al[12] to assess live kidney donors' perceived susceptibility to developing kidney disease. Participants were asked, "How likely do you think it is that you could develop kidney problems or kidney failure in the next 10 years? Possible responses included, "Not likely, Slightly likely, Moderately likely, or Very likely." Participants were also asked, "How concerned are you about developing kidney problems or kidney failure in the next 10 years?" Possible responses included, "Not concerned, Slightly concerned, Moderately concerned, or Very concerned."

Table 2. Association of sociodemographic characteristics with perceived susceptibility to chronic kidney disease among hypertensive living kidney donors, N=318

Characteristics	High-Likelihood			Strongly Concerned		
	OR	aOR (95%CI)[a]	P	OR	aOR (95%CI)[a]	[b]
Age group						
18-35 years	reference	reference		reference	reference	
36-49 years	.61	.61 (.29, 3)	.18	.68	.70 (.37, 1.33)	.27
≥50 years	.41	.39 (.18, .85)	.02[b]	.58	.60 (.31, 1.17)	.13
Sex						
Female	reference	Reference		reference	reference	
Male	1.12	1.08 (.62, 1.88)	.78	1.14	1.15 (.73, 1.82)	.55
Race/ethnicity						
White	reference	reference		reference	reference	
Black	.93	.79 (.38, 1.62)	.52	1.27	1.1 (.66, 2.14)	.57
Other	.88	.74 (.14, 3.89)	.78	.82	.71 (.16, 3.13)	.66
Highest level of education						
<College graduate	reference	reference		reference	reference	
College graduate or beyond	.86	.94 (.50, 1.77)	.85	.97	.99 (.59, 1.67)	.98
Health insurance status						
No insurance	reference	reference		reference	reference	
Any insurance	.39	.32 (.043, 2.38)	.04 [b]	1.16	1.13 (.18, 7.01)	.90
Marital status						
Single/not married	reference	reference		reference	reference	
Married/living with partner	.84	.88 (.47, 1.62)	.68	.91	.96 (.57, 1.61)	.87
Employment Status						
Full-time/part-time	reference	reference		reference	reference	
Retired	1.21	1.45 (.78, 2.69)	.24	1.30	1.50 (.89, 2.53)	.12
Unemployed	1.53	1.53 (.65, 3.63)	.33	.87	.86 (.40, 1.85)	.69
Diabetes status						
Diabetes	reference	reference		reference	reference	
No diabetes	2.43	2.27 (1.03, 5.01)	.04[b]	1.55	1.43 (.70, 2.93)	.32
Lifestyle change/self-care behavior						
On diet	reference	reference		reference	reference	.92
Medication adherent (if applicable)	.65	.66 (.33, 1.33)	.25	0.84	.88 (.48, 1.60)	.68
≥1 Self-care behavior change	.96	.92 (.41, 2.05)	.83	1.62	1.53 (.74, 3.14)	.25

OR, odds ratio, aOR, adjusted odds ratio
a. Adjusted for age, sex, and race
b. Represents P<.05 for comparison of subgroup to the reference subgroup

Behavioral Risk Factor Surveillance System Hypertension Self-Care Survey Measures

We used validated survey measures based on the Center for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS) Questionnaire[17] to assess live kidney donors' reported actions to take control of their blood pressure. Participants were asked, "Since your diagnosis, have you made any of the following lifestyle changes to take care of your blood pressure?" The lifestyle changes included, "change your diet, lose weight, cut back on your salt intake, exercise more, cut back on alcohol, and quit smoking." Possible survey responses were, "yes, no, or not applicable." Using methods similar to BRFSS,[17] we combined the six responses into a new dichotomous variable, and participants were scored based on reporting making at least one out of the six behavior changes.

Statistical Analysis

Using multivariable logistic regression models, we examined potential associations of race/ethnicity with perceived susceptibility to kidney disease, as well as with reported lifestyle chang-

es to control blood pressure, controlling for demographic factors. All analyses were performed using STATA 15/SE (College Station, Texas), and P<.05 were considered statistically significant.

Results

Sociodemographic Characteristics of Study Participants

The study included a total of 318 US-based live kidney donors who developed post-donation HTN, with 57.6% female; 78.9% White; 18.6% Black; and mean age of 46.7 years old at the time of kidney donation. The majority were aged >35 years at the time of donation (83.1%), insured (97.9%), married/living with a partner (71.4%), and employed (58.4%). Most donors did not have a college degree (74.1%) and did not have diabetes (87.5%). In addition, most study participants had been prescribed at least one anti-hypertensive medication (97.4%). (Table 1)

Perceived Susceptibility to Developing Kidney Disease

Black donors were equally as likely as White donors to report being moderately or strongly concerned about developing kidney disease (adjusted odds ratio, aOR: 1.27, 95%CI:.66, 2.14, P=.57). Donors with diabetes were more likely than those without diabetes (aOR: 2.27, 95%CI:1.03, 5.01, P=0.04), while donors aged ≥50 years were less likely than younger donors (aOR:.39, 95%CI: .18, .85, P=0.02) to report being moderately or strongly concerned about kidney disease. (Table 2)

Hypertension Self-Care Behaviors

Overall, 87.4% of donors reported taking at least one action to help control blood pressure. The majority reported a reduction in salt intake (77.4%), changes in diet (68.8%), increased exercise (65.6%), and weight loss (64.5%), while fewer donors reported smoking cessation (39.7%) or reduced alcohol intake (36.8%). (Figure 1) Among donors who expressed concerns about future kidney disease, Black donors were equally as likely as White donors to report taking at least one action to control blood pressure.

Discussion

In this study of live kidney donors with hypertension, there were no substantial differences in perceived susceptibility to kidney disease among Black and White donors, despite evidence that Black donors may experience greater risk of kidney disease in the future. Hypertensive donors with diabetes were more likely than those without diabetes to report concerns about developing kidney disease, while donors aged >50 years were less likely than younger donors to report concerns about kidney disease. Overall, relatively few study participants considered themselves to be very likely to develop kidney disease in the future. However, within our study, only 87% of donors with post-dona-

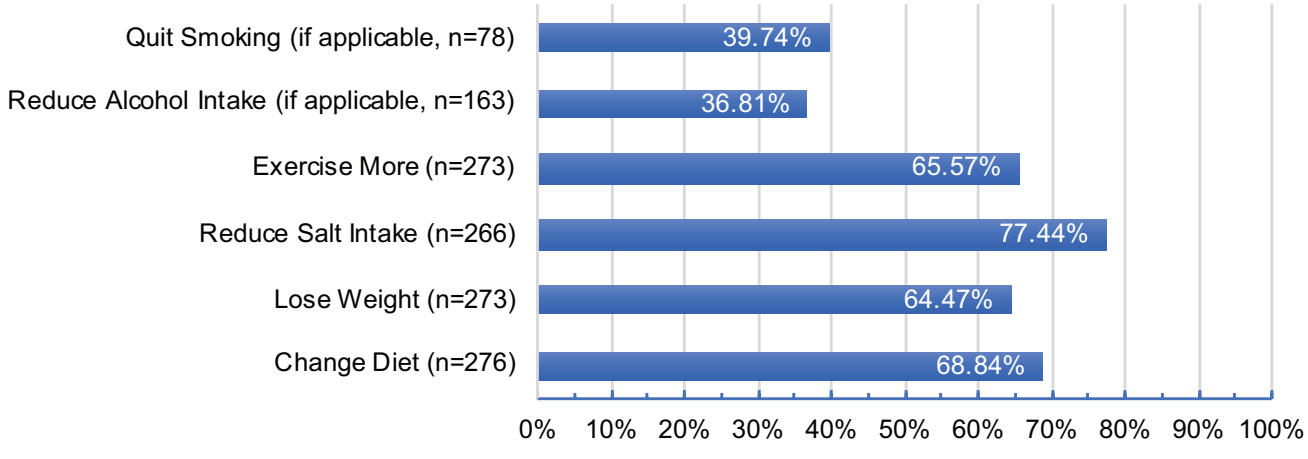

Figure 1. Reported lifestyle changes to help control blood pressure

tion HTN reported making at least one recommended HTN self-care lifestyle change, as compared with 98.1% of BRFSS survey participants in the general US population.[17] These results suggest that some live donors may lack understanding about the association of HTN with future risk of kidney disease, as well as the importance of HTN self-care behaviors. Our findings highlight the importance of comprehensive education about HTN self-management and future disease risk among live donors.

Perceived susceptibility to future disease risk has been previously associated with greater adherence to immunosuppressive medication in transplant recipients.[18] In breast cancer, researchers found that perceived susceptibility was the only mediator they tested that influenced whether or not patients underwent a mammogram.[19] Researchers in Taiwan who examined medication adherence among transplant and dialysis patients also reported that perceived susceptibility to future disease was associated with adherence rates.[18] However, prior work found that awareness and perceived risk of developing kidney disease is generally low in the United States.[20,21] Boulware et al[12] also reported low perceived risk and concerns about kidney disease among high-risk primary care patients diagnosed with HTN in the general population. Our study contributes to the kidney literature by examining factors associated with concerns about kidney disease and HTN self-care behaviors among live kidney donors.

Our study results indicate that live donors with HTN may also benefit from coordinated efforts to improve kidney health education and to increase self-management.

Behavioral interventions to enhance knowledge about future disease risk, attitudes, and self-care strategies among live kidney donors may be beneficial. Barriers to chronic kidney disease education exist in primary care; efforts targeting barriers may improve overall kidney health and prevent kidney failure.[22] Within the live kidney donor community, there are current recommendations to develop a unified policy on donor follow-up by the United Network for Organ Sharing and Kidney Disease Improving Global Outcomes.[23] Our study results indicate that live donors with HTN may also benefit from coordinated efforts to improve kidney health education and to increase self-management. One example of a comprehensive program to increase awareness about the risk of chronic kidney disease that donors could be linked into is the National Kidney Disease Education Program.[23] Other novel interventions among the transplant recipient population benefit from the integration of technology to improve medication adherence.[24-26] Future efforts could work to expand the use of similar technology to enhance self-care behaviors among live kidney donors living with chronic conditions.

Our null study findings of no statistically significant differences in perceived susceptibility or reported self-care behaviors between Black and White living kidney donors suggest that there may be additional factors influencing documented racial/ethnic differences in HTN sequelae among living kidney donors.[27,28] As noted within the general US population, multi-level factors influence the presence of HTN disparities, ranging from the individual patient level to the family, friends, and social level; the provider and organizational level; and the policy and community level and include the effects of structural racism.[29,30] Complex factors, such as differences in access to care and quality of care, may also influence HTN disparities in the living donor population. Future research is needed to better characterize mechanisms influencing disparities in HTN among living kidney donors.

Study Limitations

Our study has several strengths. The first is the ability to comprehensively analyze long-term health outcomes among a diverse sample of live kidney donors in the United States. Few data sources exist for live kidney donors that capture electronic medical record data from both transplant centers and primary care providers. In addition, our study was enhanced by rich survey data to more comprehensively examine factors associated with future disease risk among live donors who were diagnosed with hypertension. A limitation of our

study is the cross-sectional nature of our survey data. The survey data are also self-reported and subject to social desirability bias. Another limitation is the relatively smaller sample of Black donors, as compared with White donors. However, we recognize that White donors comprise a larger proportion of live donors in the US. Notwithstanding these constraints, our study is among the first to examine perceived susceptibility to kidney disease and HTN self-care behaviors among live donors.

Conclusion

There were no differences in perceived susceptibility to kidney disease or engagement in self-care behaviors in this study of Black and White live kidney donors diagnosed with hypertension. In addition, donors in this study were less likely to engage in at least one HTN self-care behavior than participants within the BRFSS population survey. These findings suggest that live kidney donors may have unique health challenges that require tailored educational approaches. Interventions to enhance knowledge about future risk of kidney disease and the importance self-care may be beneficial.

Acknowledgements

The authors sincerely thank the research investigators and participants of the Wellness and Health Outcomes in the Live Donor (WHOLE-Donor) Cohort Hypertension Care Study. The WHOLE-Donor Cohort site principal investigators include Drs. Dorry Segev and Allan Massie (Johns Hopkins University), Drs. Jayme Locke and Rhiannon Reed (University of Alabama at Birmingham), Dr. Gaurav Gupta (Virginia Commonwealth University), Dr. Matthew Weir (University of Maryland), Drs. Matthew Cooper and Jennifer Verbesey (Georgetown University), and Dr. John Friedewald (Northwestern University).

The authors were supported by grant K01HS024600 (PI: Purnell) from the Agency for Healthcare Research and Quality (AHRQ); and by grants R01DK096008 (PI: Segev), K01DK114388 (PI: Henderson), K01DK101677 (PI: Massie), and K24DK101828 (PI: Segev) from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The funders of the study had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript or the decision to submit for publication.

Author Contributions

Research concept and design: Gianaris, Vargas, Yu, Massie, Levan, Segev, Purnell; Acquisition of data: Gianaris, Johnson, Jackson, Massie, Levan, Segev, Purnell; Data analysis and interpretation: Gianaris, Vargas, Johnson, Yu, Wilson, Perkins, Jackson, Boulware, Massie, Levan, Segev, Purnell; Manuscript draft: Gianaris, Vargas, Johnson, Wilson, Perkins, Boulware, Segev, Purnell; Statistical expertise: Gianaris, Vargas, Yu, Jackson, Massie, Segev, Purnell; Acquisition of funding: Levan, Segev, Purnell; Administrative: Vargas, Johnson, Wilson, Perkins, Boulware, Massie, Levan, Segev, Purnell; Supervision: Segev, Purnell

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