

BMJ Open Exploring barriers to living donor kidney transplant for African, Caribbean and Black communities in the Greater Toronto Area, Ontario: a qualitative study protocol

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ABSTRACT

Introduction Living donor (LD) kidney transplant (KT) is the best treatment option for many patients with kidney failure as it improves quality of life and survival compared with dialysis and deceased donor KT. Unfortunately, LDKT is underused, especially among groups marginalised by race and ethnicity. African, Caribbean and Black (ACB) patients are 60%–70% less likely to receive LDKT in Canada compared with white patients. Research from the USA and the UK suggests that mistrust, cultural and generational norms, access, and affordability may contribute to inequities. To date, no Canadian studies have explored the beliefs and behaviours related to LDKT in ACB communities. Research approaches that use a critical, community-based approach can help illuminate broader structural factors that may shape individual beliefs and behaviours. In this qualitative study, we will investigate barriers to accessing LDKT in ACB communities in the Greater Toronto Area, to enhance our understanding of the perspectives and experiences of ACB community members, both with and without lived experience of chronic kidney disease (CKD).

Methods and analysis Hospital-based and community-based recruitment strategies will be used to recruit participants for focus groups and individual interviews. Participants will include self-identified ACB individuals with and without experiences of CKD and nephrology professionals. Collaboration with ACB community partners will facilitate a community-based research approach. Data will be analysed using reflexive thematic analysis and critical race theory. Findings will be revised based on feedback from ACB community partners.

Ethics and dissemination This study has been approved by the University Health Network Research Ethics Board UHN REB file #15-9775. Study findings will contribute to the codevelopment of culturally safe and responsive educational materials to raise awareness about CKD and its treatments and to improve equitable access to high-quality kidney care, including LDKT, for ACB patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Community-based approach to study design fosters relationships between academic and community partners.
- ⇒ Theoretically informed data analysis goes beyond documentation of health inequities.
- ⇒ Reflexive data analysis examines biases and challenges assumptions of the research team.
- ⇒ Inclusion of diverse participant perspectives, for example, gender, age, representation from diverse African, Caribbean and Black communities (but not all), patients, healthcare professionals and community members without lived experience of kidney disease.
- ⇒ Community partners were not involved in the initial phases of study design.

INTRODUCTION

From a medical perspective, living donor kidney transplant (LDKT) is considered the best treatment for many patients with kidney failure who require kidney replacement therapies (dialysis or kidney transplant (KT)).¹ LDKT is associated with better quality of life, graft survival and life expectancy compared with dialysis.^{1–7} LDKT is also associated with shorter wait times compared with deceased donor KT.¹ Importantly, along with medical considerations, major treatment decisions (such as LDKT) can also include financial, social, emotional and cultural considerations.⁸ LDKT is underused internationally and in Canada,⁹ especially among groups marginalised by race and ethnicity.^{10,11} Specifically, African, Caribbean and Black (ACB) patients are 60%–70% less likely to receive LDKT in Canada compared with white patients.^{11–13}



ACB communities represent 4.6% of the population of Canada and include generations of Canadians, recent immigrants from Africa and the Caribbean, individuals of Afro-Indigenous origin and diasporic ACB communities who identify with various ethnic and geographical regions.^{14 15} While these are diverse communities based on countries of origin, immigration status, religion and culture, they are all likely to face systemic anti-black racism both within and outside the healthcare system.¹⁶

Racism and discrimination against ACB individuals remain deeply entrenched and normalised in Canadian institutions, policies and practices.¹⁷ For example, a landmark police report revealed that ACB individuals in Toronto are overrepresented among victims of police use of force.¹⁸ The COVID-19 pandemic further unveiled systemic anti-black racism and long-standing inequities faced by ACB communities in Toronto.^{19–23} ACB Canadians experience higher incidence of diabetes and hypertension compared with the general population.^{24 25} This may be related, in part, to the stress associated with discrimination and anti-black racism which in turn can contribute to higher rates of chronic kidney disease (CKD) in this population.^{24 25}

In the USA and the UK, studies have shown that mistrust in physicians and the healthcare system, cultural and generational norms, access and affordability substantially limit accessing KT and LDKT among ACB patients.^{26–29} Although these studies provide valuable insights, we cannot directly extrapolate these findings to Canada because there are fundamental differences in the social, environmental and healthcare systems between Canada, the USA and the UK.

However, despite the repeatedly documented inequities in access to KT and LDKT, no academic research studies have been conducted in Canada to explore and understand the factors that influence beliefs and behaviours around KT and LDKT in ACB communities. For example, respect for death-related rituals and rites, and concern about the religious permissibility of KT are likely to create hesitation among Muslim Canadians who comprise an increasing proportion of ACB communities. In addition, individuals may prefer to obtain donation directly from members of their community because of their experiences with racism, oppression and mistrust of the healthcare system.³⁰ Moreover, individuals may feel alienated from the healthcare system due to its dominantly Eurocentric approaches that privilege biomedical care with little consideration for socio-environmental conditions influencing health outcomes. Such topics are best explored using qualitative research methods.

A better understanding of the perspectives and experiences of ACB patients and families, healthcare professionals (HCPs) and community members will facilitate the tailoring of information and clinical pathways to the needs of ACB patients.

Aims

The purpose of our study is to identify barriers to accessing LDKT in ACB communities in the Greater Toronto Area (GTA), Ontario. The objectives of the study are to explore study participants' perspectives on and experiences with the health and kidney care system, CKD, kidney failure and its treatments, particularly LDKT, to deepen our understanding of the perspectives and experiences of ACB community members—both with and without lived experience with kidney disease. Ultimately, we wish to generate knowledge to inform the codevelopment (with ACB community partners) of culturally safe and responsive educational materials to raise awareness about CKD, kidney failure and its treatments, and to ensure equitable access to the best kidney care for ACB patients.

METHODS AND ANALYSIS

Study design

We will conduct an exploratory, qualitative study including focus groups and individual interviews with self-identified ACB individuals both with and without lived experience of CKD.

Setting and context

ACB individuals with lived experience of CKD who previously participated in quantitative research conducted by our team, and who have indicated their interest in participating in focus groups or interviews will be invited to participate in this qualitative study. We previously conducted a cross-sectional study to assess psychosocial and ethnocultural barriers to accessing LDKT among patients with CKD. All ACB patients referred for pre-KT assessment from various renal programmes across the GTA, as well as potential KT candidates treated with maintenance dialysis from renal programmes at the Toronto General Hospital, St. Michael's Hospital, Humber River Hospital or Scarborough General Hospital were eligible to participate in the study. Of these, any individuals who indicated interest in participating in focus groups or interviews will be contacted by a member of the qualitative research team and invited to participate in the current study. Collaboration with our community partner, Black Health Alliance (<https://blackhealthalliance.ca/>), a community-led registered charity that works to improve the health and well-being of ACB communities, will facilitate recruitment of individuals with no connection to CKD.³¹

Sample and recruitment

We have chosen to speak with individuals from three mutually exclusive groups of participants, whom we anticipate may have unique perspectives on CKD, kidney failure and kidney replacement therapies such as LDKT: individuals with lived experience with CKD, general community members with no known lived experience of CKD and nephrology professionals with no known lived experience of CKD (eg, physicians,

nurse practitioners, nurses). All three groups likely have experiences with racialisation, and their relationship with CKD and kidney care is likely to help shape their perspectives. Purposive and snowball sampling will be used to recruit study participants. Study recruitment has been impacted by the COVID-19 pandemic and its effects on in-person data collection, the disproportionate burden on ACB communities, and the increased workload of HCPs. The pandemic has had a detrimental impact on the ability to recruit study participants and conduct in-person focus groups. Additionally, the increased burden on ACB communities and HCPs as a direct result of the pandemic resulted in further recruitment challenges. As a result, we ceased in-person data collection soon after the pandemic started and will conduct virtual data collection via telephone and MS Teams when we can safely resume doing so which will be in line with recommendations of participating hospitals and community partners.

Individuals with lived experience with CKD

Individuals who self-identify as members of ACB communities with lived experience with CKD (eg, individuals with kidney failure before or on dialysis, waitlisted for KT, KT recipients, family members of patients with kidney failure, living kidney donors and individuals undergoing living donor evaluation) will be invited to participate in focus groups and/or individual interviews. We aim to hold 5–6 focus groups with 6–8 participants per group.

ACB community members with no lived CKD experience

We will also invite self-identified ACB community members with no known lived experience of kidney disease to participate in the study. We aim to hold 5–6 groups with 6–8 participants per group. The rationale for speaking with this group is that anyone may be considered a potential living donor; therefore, it is important to understand their perspectives and experiences regarding CKD, KT and organ donation.

Healthcare professionals

Finally, we will interview 8–10 nephrology professionals who self-identify as ACB community members. We have chosen to interview HCPs individually since it can be challenging to coordinate focus groups with this particular participant group. The rationale for speaking with this group is to understand their unique perspective as ACB community members and HCPs with intimate knowledge of the kidney care pathway.

The inclusion criteria for all three participant groups are as follows: self-identified members of ACB communities, ≥18 years of age, able to speak and understand English. The exclusion criteria are as follows: unwilling or unable to provide informed consent and, in the case of the second group (individuals with lived experience of CKD), dementia or significant mental delay/challenge as identified by the individual's healthcare team.

Study recruitment will occur via hospital-based methods, such as the posting and distribution of flyers and in-clinic study recruitment efforts. The research team will also collaborate with community partners and a community engagement specialist (L-JM) with close ties to ACB communities, who will use established connections to extend personal invitations to participate in the study. Study recruitment will benefit from the established and trusted relationships that both our community partners and community engagement specialist have with diverse ACB communities.

Potential study participants will be approached by a member of their healthcare team (in the case of the first participant group) or a community host known to the community engagement specialist (eg, community leader, social influencer) in the case of the second participant group. The community host will be a trusted individual who will act as a liaison between the community engagement specialist and the study participants. The host will help to plan, organise, and schedule the groups, answer questions and assist with practical matters at the time of the focus group. For the third participant group, potential participants will be identified by study coinvestigators and contacted by a research team member. Once potential study participants have agreed to learn more about the study, they will be connected to a qualitative team member who will provide further details, answer questions, and address any concerns about the study.

Information regarding the study and invitations to participate will be distributed in person, as well as via existing communication channels of our community partners, such as direct person-to-person contact through phone, in-person communication and online messaging platforms such as email, Facebook Messenger and WhatsApp; informational sessions with interested groups who request the opportunity to hold a focus group during regularly scheduled meetings; and connecting to new community groups and partners to inform them of the opportunity to participate in the study. In an attempt to maximise the diversity of the sample, we will connect with various ethnic groups within ACB communities, including: Jamaican, Haitian, Somalian, Nigerian, Ethiopian, Ghanaian, Caribbean and Sudanese. Consideration will also be given to ensure representation across age, immigration status, religion, gender and geographical region in the GTA.

Theoretical framework

This study was not initially designed in collaboration with ACB community partners; however, as a result of discussions with the community engagement specialist and other collaborators, the study evolved from a more traditional institution-driven approach to one that is informed by the principles of community-based participatory research (CBPR) to guide data collection, data analysis and dissemination of study findings.^{32 33} CBPR is a research paradigm which integrates education and social action to improve health and reduce health disparities.³²

CBPR focuses on relationships between academic and community partners, with principles of colearning, mutual benefit and long-term commitment with the aim of incorporating community theories, participation and practices into the research efforts.³³

Critical race theory (CRT)^{34 35} will be used during data analysis to understand how the experience of ‘race’, and by extension, racialisation influence the perspectives and experiences of study participants regarding accessing or considering healthcare and specifically, kidney care and LDKT. The term ‘racialisation’ emphasises the complex historical, social and political processes that result in unequal power distribution between groups. The term ‘racialised’ refers to individuals in groups that are socially and politically constructed as distinct from the ‘reference’ group or the one holding the majority of the economic, social and political power.

Racialised individuals face implicit or overt bias, micro-aggression and macroaggression, racism, and discrimination, including during their interactions with the healthcare system. These experiences and interactions are also related to health inequities.^{36–39} Critical race research and interventions in the health sector must go beyond merely documenting disparities and instead seek to uncover the causes of health disparities; how racialisation shapes disciplinary conventions; and how knowledge is produced within the existing, inequitable frameworks, in order to better understand and to challenge the existing power hierarchies.⁴⁰ Accordingly, we will draw on four tenets of CRT in our data analysis:

Racial consciousness

The research team will approach the analysis with the knowledge that race and racialisation are salient realities that shape the lived experiences of members of ACB communities both within and outside of the healthcare system. This racial consciousness is also informed by an understanding of anti-black racism which is evident in prejudicial attitudes and beliefs, and operationalised in stereotyping and discrimination that are directed at people of African descent and rooted in the unique history and legacy of colonisation, enslavement and racial stratification which continue to impact the experiences of Canadians today, and racialised individuals in particular.^{41 42}

Social, geographical and temporal location

The research team will bear in mind that Canada’s race relations are greatly informed by the existence of a particular type of racism often dismissed because of the country’s identity as being ‘polite’, ‘friendly’ and ‘tolerant’. While Canada prides itself on its ethos of multiculturalism, discrimination against ACB individuals remains deeply entrenched and normalised in Canadian institutions, policies, programmes and practices.¹⁷ Until relatively recently, public opinion was that racism did not exist in Canada; however, the murder of George Floyd, an unarmed African American man, by a white police officer

in the USA in 2020 prompted worldwide protests, the further rise of the Black Lives Matter movement,⁴³ and an increasingly open public discourse about the enduring existence of anti-black racism in Canada. As Marie-Claude Landry, the Chief Commissioner of the Canadian Human Rights Commission stated, ‘It is time for all Canadians to acknowledge that anti-Black racism is pervasive in Canada. In fact, the belief that there is little to no racism in Canada is in itself a barrier to addressing it’.⁴⁴ Similarly, Prime Minister Justin Trudeau stated in his 2022 Emancipation Day (August 1) communiqué: ‘Although slavery was abolished nearly 200 years ago, its effects continue to live on today. The legacy of systemic anti-Black racism is still embedded throughout our society, including in our institutions’.⁴⁵ Indeed, Canada has a long history of systemic racism including colonialism, the trans-Atlantic slave trade, the Indian Act, Residential Schools and more.

Power relations and processes

The research team will also approach this analysis with an understanding of how race, racism and racialisation are manifested both within and outside of institutional settings, and how individual, institutional and societal racism are interlinked and operating systemically—generating systemic racism—which in turn produce and reproduce the social structures that mediate the lives of individuals.

Counternarratives as valid data

Lastly, the research team will acknowledge, respect and accept the experiences of ACB community members that are shared during interviews and focus group sessions—taking them as valid data that serve to disrupt existing institutional perspectives. Elements of CRT will be employed in the analytical process to expose and challenge the mechanisms by which racism produces inequities in access to healthcare in general and to LDKT, specifically. Ultimately, we will seek to centre the multiple and diverse lived experiences of the study participants in order to disrupt ideas that may be commonly taken for granted by the healthcare system regarding the inequitable access to LDKT experienced by ACB communities in the GTA.

Research team

The research team consists of a diverse group of individuals from different ethnocultural backgrounds (including ACB communities) and varying degrees of educational and professional training and experiences which confer power and privilege in numerous ways. Please see online supplemental appendix A for positionality statements from all coauthors. The community engagement specialist and the qualitative lead will conduct all focus groups and interviews with support from community partners and qualitative research team members.

Data collection

Focus groups and interviews

Informed consent and demographic information (see online supplemental appendices B and C) will be obtained from study participants prior to their participation in focus groups and interviews. Participants will be given the opportunity to ask questions and obtain assistance in completing consent forms and demographic questionnaires. In addition to the hospital environment, focus groups and interviews will also be held in community locations. If necessary, virtual (MS Teams) or telephone options will be offered. For in-person focus groups, food incorporating the culture of the participant group will be provided, when possible, to foster a comfortable atmosphere for participants and to support ACB-owned businesses. When necessary, child-care, language translation (for words or short phrases) and accommodation for specific meal observances will be provided. Necessary support and resource materials will be available to participants after focus groups or interviews sessions. Due to the sensitive nature of the research, it is a priority of the research team to create both a psychologically and culturally safe environment for participants. We will also aim to respect community norms around meetings; as such, focus groups will be conducted in conjunction with existing meetings. Study participants will be provided with \$C30 honoraria as a token of our appreciation.

Focus group/interview discussion guide

Semistructured focus group/interview guides (see online supplemental appendices D and E) were developed by the research team based on clinical experience, literature review and discussion with community partners. Focus groups were originally focused on perspectives of kidney disease, treatment options for kidney failure and experiences of kidney care. Revisions to the focus group guide resulted in the addition of an introductory discussion about ethno-racial identity, health and the Canadian healthcare system. This is particularly important for the general community focus groups, since the majority of these participants will have no direct connection to kidney disease or transplant. The focus group moderators will then guide the discussion into topics related to kidney disease, KT and LDKT and organ donation. Moderators will ask open-ended questions designed to explore the participants' views on the topics of interest and stimulate discussion and group interaction among participants.

As is common in qualitative research, not all questions will be asked the same way, in the same order during each focus group or individual interview, and participants will be encouraged to take the discussion in different directions if desired. Moderators and interviewers will be responsible for maintaining the flow and focus of the conversations, while enabling study participants, as experts in their own lives and experiences, to speak about topics they deem relevant and important.

Focus group moderator/interviewer training

To prepare for focus group moderation, the primary focus group moderator (the community engagement specialist) and additional comoderators (representatives from community partner organisations and research students) have been provided with focus group training by the qualitative research lead (BE). The community engagement specialist and community partners have also provided the qualitative research team with information and resources on conducting culturally responsive research with ACB communities. For example, although it is common for a focus group moderator to interrupt a study participant who is dominating the conversation in order to give all participants the opportunity to speak, might not occur in all cases, since interrupting a participant, particularly a community elder, may be viewed as rude and could erode trust between the research team and the focus group participants.

Focus group comoderators will be responsible for note-taking, asking follow-up questions and assisting with language translation if necessary. Regular debriefing regarding data collection will occur between the qualitative team and the community engagement specialist throughout the duration of the study. All focus groups and interviews will be audio recorded, transcribed verbatim, verified and deidentified for data analysis. Hard copy data will be stored in locked filing cabinets at the University Health Network (UHN) and electronic data will be stored on secure UHN servers. Data management and analysis will be facilitated by the use of NVivo V.12 software (QSR International) designed to assist with the storage, organisation and analysis of qualitative data.

Data analysis

Data will be analysed using reflexive thematic analysis (RTA),^{46 47} which will result in the development of themes that are reflective of the data as a whole. The goal of this approach is to move from a detailed, descriptive level of analysis to a broader, more thematic level. Data analysis will begin in conjunction with data collection and will be informed by the tenets of CRT. Data collection will cease when the research team determines that the study sample holds enough information power, meaning the volume and quality of the data are sufficient to address the research objectives.^{48 49} The reflexive aspect of RTA is particularly relevant due to the diversity of our team and effects of our varying social positions on data interpretation.⁵⁰ We wholeheartedly view this as a strength, rather than something to be mitigated, and will actively engage in reflexivity exercises throughout the analysis to account for how our individual subjectivities influence study findings.⁵⁰

We will also be fortunate to have continuous input from our community engagement specialist and community partners throughout the duration of the study, which will include both formal team presentations as well as informal discussions during analytical sessions and other meetings. The research team has participated in antiracism and



antioppressive training. Finally, we will regularly engage in discussions regarding power relations, as they arise in research partnerships between community organisations and academic institutions such as universities and hospitals.

RTA is also deemed a suitable choice of analytic method due to its strong grounding in qualitative philosophies, as well as its alignment with applied qualitative health research. The process of RTA consists of six phases: (1) familiarisation, (2) generation of initial deductive and inductive codes, (3) construction of themes, (4) review of potential themes, (5) naming and defining themes and (6) production of the final report.^{46 47} In order to identify patient-level and institutional-level barriers, including the impact of various forms of racism on those considering KT and LDKT, we will generate a coding framework which includes both deductive and inductive codes, in that some of our codes will be predetermined based on the literature and our theoretical framework; and others will be generated directly from the data. This coding framework will be revised as our analysis progresses and final codes will be applied to all of the data.

Emerging ideas will be discussed in diverse, expanding circles, that is, research seminars, community town halls. We will actively seek feedback as our analysis progresses to ensure the rigour and trustworthiness of the study and its findings.

Patient and public involvement

Both patient and community partners have been involved in the study design and will be involved in how the study is conducted as described above. We will adhere to the principles of community-based research principles to facilitate a collaborative and equitable partnership that fosters colearning and capacity-building among all partners—with the goal of generating knowledge that will benefit everyone involved. Patient and community partners will be asked to review and disseminate study findings. Importantly, we will seek advice from patient and community partners on how and where to disseminate study findings beyond the traditional academic routes such as conferences and publications.

ETHICS

Ethical approval for this study was obtained from the University Health Network Research Ethics Board (UHN REB #15-9775) and from the ethics boards of participating hospitals (#2016-011 M; #16-249; #NEP-18-016). All study procedures will be conducted in accordance with the standards of the UHN REB and the 1964 Declaration of Helsinki and its later amendments. No study procedure will begin until the study participant has provided informed consent and participants can leave the study at any time and for any reason without any consequences. Data will be stored in a deidentified manner to minimise any breaches in patient confidentiality.

Impact and dissemination

This study seeks to identify barriers to accessing LDKT in ACB communities in the GTA, Ontario. The objectives of the study are to explore participants' perspectives on and experiences with the healthcare system, CKD and kidney failure, and kidney replacement therapies, particularly LDKT. We want to gain a deeper understanding of the perspectives and experiences of ACB community members, including those with and without lived experience of CKD and kidney care. Ultimately, we wish to generate knowledge and collaborate with ACB community partners to codevelop culturally safe and responsive educational materials and clinical pathways to help raise awareness about CKD and kidney replacement therapies (especially LDKT), and to improve equitable access to the best kidney care for ACB individuals with kidney failure. The final dissemination plan will be determined by study coinvestigators and patient and community partners, and will likely include various formats and locations, such as patient and community forums, national and international meetings, peer-reviewed journals, and conference presentations. Study participants will receive reports generated by the study if they wish and where possible.

Study status

The study is ongoing. Participants of the 'Barriers' study (UHN REB #15-9775) participated in in-person focus groups in 2018 and 2019. From 2020 onwards, adult members of the ACB community, ACB individuals with lived experience of CKD, and nephrology professionals are being recruited for in-person and virtual focus group and individual interviews. Additional potential participants are being identified on an ongoing basis by clinical teams at participating hospitals. Recruitment through both hospital-based methods and community partnerships will continue for additional focus group and interview participants. Data collection and analysis are ongoing and community partner check-ins are planned for 2023. Additional interviews and focus groups will be completed by 31 December 2023 which is set as a target end date for study recruitment.

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in regular team meetings to support this research project. All authors provided input into the protocol, critical feedback on the manuscript and approved the final manuscript.

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