Received: 1 February 2023 | Revised: 23 April 2023 | Accepted: 23 April 2023

DOI: 10.1111/trf.17396

BLOOD DONORS AND BLOOD COLLECTION

TRANSFUSION

Sickle cell disease and the need for blood: Barriers to donation for African, Caribbean, and Black young adults in Canada

Jennie Haw[1,2] | **Jean Walrond**[3] | **John Jayachandran**[4] | **Dzifa Dordunoo**[5] | **Hannah Eche-Ameh**[3] | **Ufuoma Muwhen**[6] | **Princess Phiri**[3] | **Jaya Rastogi**[1] | **Biba Tinga**[7]

[1]Department of Health Sciences, Carleton University, Ottawa, Ontario, Canada

[2]Donation Policy and Studies, Canadian Blood Services, Ottawa, Ontario, Canada

[3]Sickle Cell Foundation of Alberta, Edmonton, Alberta, Canada

[4]Department of Sociology, Concordia University of Edmonton, Edmonton, Alberta, Canada

[5]School of Nursing, University of Victoria, Victoria, British Columbia, Canada

[6]Department of Biological Sciences and Psychology, University of Alberta, Edmonton, Alberta, Canada

[7]Sickle Cell Disease Association of Canada, Toronto, Ontario, Canada

Correspondence

Jennie Haw, Donation Policy and Studies, Canadian Blood Services, 1800 Alta Vista Drive, Ottawa, ON K1G 4J5, Canada.

Email: jennie.haw@blood.ca

Funding information

Social Sciences and Humanities Research Council of Canada

Abstract

Background: Many blood operators around the world face the challenge of increasing the number of donors of African ancestry to meet the transfusion needs of people living with sickle cell disease. This article reports results of the barriers to blood donation for young adults (aged 19–35) in Canada who identify as African, Caribbean, or Black.

Study Design and Methods: A community-based qualitative study was conducted by researchers from community organizations, blood operator, and universities. In-depth focus groups and interviews ($n = 23$) were conducted from Dec 2021 to Apr 2022 and thematic analysis was completed.

Results: Applying a socio-ecological model, multiple levels of interacting barriers to blood donation were identified. These included macro-level barriers (e.g., systemic racism, mistrust of the healthcare system, sociocultural beliefs and views about blood and sickle cell disease), mezzo-level barriers (e.g., deferral criteria, minimum hemoglobin levels, donor questionnaire, access, parental concerns), and microlevel barriers (e.g., limited knowledge of blood needs for people with sickle cell disease, lacking information about blood donation process, fear of needles, personal health concerns).

Discussion: This study is the first to focus on barriers to donation for African, Caribbean, and Black young adults across Canada. Parental concerns, informed by parents' experiences of inequitable healthcare and mistrust, emerged as a novel finding in our study population. Results suggest that higher order (macro-level) barriers influence and may reinforce lower order (mezzo- and microlevel) barriers. As such, interventions aimed at addressing barriers

Abbreviations: CAC, community advisory committee; CBR, community-based research; CBS, Canadian Blood Services; H-Q, Héma-Québec; SCD, sickle cell disease; SCDAC, Sickle Cell Disease Association of Canada; SCFA, Sickle Cell foundation of Alberta.

to donation should keep in view all levels with particular attention paid to higher order barriers.

KEYWORDS
donors, health research methodology

1 | INTRODUCTION

In Canada, approximately 6000 people live with sickle cell disease (SCD), with 1 in every 2500 babies born in Canada projected to have SCD.[1] A genetic condition that causes sickling of red blood cells, SCD is more prevalent in people originating from Africa, the Caribbean, Mediterranean, Middle East, Southeast Asia, Western Pacific Region, and South and Central America.[2] While a stem cell transplant is available for some individuals, there is no universal cure for SCD. Many people with SCD rely on blood transfusion with some requiring monthly red cell exchange (i.e., 8–10 units of blood) as part of their treatment. The closer the blood-type match between the donor and recipient, the less likely the recipient with SCD will experience adverse health effects, such as alloimmunization.[3] Because blood antigens are inherited, close matches are most often found in donors who share similar genetic ancestry with the recipient.

Canadian Blood Services (CBS) and Héma-Québec (H-Q) are the two blood operators in Canada. CBS serves all provinces and territories except for the province of Quebec, which is served by H-Q; both rely on voluntary, nonremunerated blood donors. Canada is a settler nation and continues to rely heavily on immigration, resulting in an -ancestrally diverse population with just under 70% identifying as White.[4] Approximately 77% of CBS' blood donors identify as White, with roughly 1% identifying as Black. This poses a potential challenge for the current donor pool to meet the needs of people with SCD who are of African ancestry. Roughly, 3.5% of the Canadian population identify as Black, and this percentage is expected to increase to 5.0%–5.6% of the population by 2036.[5] As such, it is likely that the need for blood to treat people with SCD will increase over time.

Race is a social construct that has been misrepresented as biology. As such, “Black race” has been used to describe people of African ancestry even when it does not necessarily describe their genetics.[6,7] Throughout this article, we use the term “African ancestry” to refer to communities and individuals of similar genetic ancestry. Where we use “African, Caribbean, or Black,” we refer to people's self-identification or social identity.

Countries such as Canada that rely on high levels of transnational migration face the challenge of recruiting donors of African ancestry. Research from the United States, Australia, France, the Netherlands, and the province of Quebec demonstrates that barriers to blood donation for people classified or identifying as Black include factors such as not knowing a blood recipient, fear of needles, other deferral criteria, mistrust of the medical system, experiences of systemic racism, cultural meanings, being unfamiliar with voluntary blood donation, and accessibility challenges.[8–15] Haitians, classified or identifying as Black, in Quebec reported that the unwarranted exclusion from blood donation during the tainted blood crisis of the 1980s continues to discourage donation in their communities today.[16,17] Despite barriers, participants indicated willingness to donate when they know there is a need for blood and that their blood may be used to help someone within their community.[16,17]

This current project is informed by a social constructivist approach that views blood donation as a social practice shaped by personal and social meanings, and broader systems and structures within which blood systems operate.[18–20] On this view, donation is a complex social process and barriers to donation are context and population specific[21]; therefore, it is necessary to understand barriers for specific populations within their local setting.[8] While a pilot study had been conducted on barriers to donation for non-White young adults in Edmonton, no published research has been conducted on barriers to blood donation for young adults of African ancestry in Canada. As such, the aims of the broader project included understanding barriers and enablers to donation, and views on donor recruitment materials for young adults of African ancestry.

Reported here are results on the barriers to donation for African, Caribbean, and Black young adults in Canada. We applied a socio-ecological framework[22,23] in our analysis to conceptualize the relationship between different barriers to donation. According to this framework, individual decisions or actions are shaped by the interactions of one's personal experiences, meanings, and attitudes with external structures and systems.

2 | STUDY DESIGN AND METHODS

This project applied a qualitative community-based research (CBR) approach. CBR is a collaborative methodology that emphasizes co-learning between researchers and participants, reciprocity in transfer of expertise, sharing of decision-making power, and action. This methodology aims to produce actionable knowledge to benefit communities involved.[24,25]

The Sickle Cell Disease Association of Canada/Association d'anémie falciforme du Canada (SCDAC) and Sickle Cell Foundation of Alberta (SCFA) initiated this project based on community needs. Leaders of both organizations were on the research team and worked together with CBS and university researchers on all aspects of the research project including identifying research priorities, developing the study design, submitting a grant application, interpreting results, and producing outputs. A Community Advisory Committee (CAC) was formed to provide additional guidance on this project and to assist with recruitment of study participants. CAC members self-identified as African, Caribbean, or Black and had an interest in and/or lived experience with SCD and/or blood donation. Research team and CAC members met to discuss the study design and the interview guide. Results and interpretation were discussed with CAC members, and they were invited to co-author on publications.

2.1 | Participant recruitment and data collection

Participants were recruited using purposive and snowball sampling strategies. CAC and research team members shared the recruitment poster with their social and professional networks through social media (e.g., Facebook, Instagram, and Twitter), and through direct email to people in their networks. Inclusion criteria were as follows: (1) 19–35 years old (inclusive); (2) self-identifying as African, Caribbean, or Black; (3) comfortable in English; and (4) living in Canada. Participants were not required to have experience as a blood donor to participate.

Research team members from sickle cell associations recommended focusing on young adults (up to age 35) since this group is considered less likely to be ineligible due to blood donation deferral criteria and could potentially become life-long donors. The lower age limit was 19 to meet age of majority in all provinces. Self-identifying as African, Caribbean, or Black was specified based on input from the CAC that people of African ancestry may self-identify in different ways. This is not an exhaustive list of possible social identities nor are they mutually exclusive; however, the research team and CAC agreed that these categories would serve study purposes.

Interested participants completed a pre-screening questionnaire hosted on Qualtrics to confirm eligibility, provide their gender, the city and province in which they live, and whether they had donated or tried to donate before. Twenty-three participants were included in this study (two focus groups with two participants each, 19 interviews). The initial intent was to conduct focus groups and offer an interview only to those who preferred not to participate in a group and/or could not attend a focus group due to scheduling conflicts. However, due to challenges with recruitment and scheduling focus groups, the decision was made to interview participants at their convenience as soon as they completed the pre-screening questionnaire. Focus groups and interviews were conducted from December 2021 to April 2022. Guided by study aims, topics explored included awareness of blood donation, barriers and enablers to donation, awareness of SCD, views on recruitment materials, and sharing and receiving information. All focus groups and interviews were between 45 and 90 min, conducted on Zoom, and audio-recorded with participant's consent. Audio-recordings were transcribed by a professional transcriptionist. Participants were offered a $20 e-gift card. Research ethics board approvals were obtained from Carleton University (Ottawa, ON) and Concordia University of Edmonton (Edmonton, AB).

2.2 | Data analysis and study participants

Data from focus groups and interviews were coded and analyzed together. Given that focus groups were dyads, each participant answered all questions, and the analysis for this article focused on what they shared about barriers to donation and not on group dynamics. Analysis was informed by grounded theory and thematic analysis, which are consistent with a social constructivist approach whereby data are interpreted and analyzed for emergent themes.[26,27] For this analytic approach a sample size between 20 and 30 is generally considered sufficient to reach data saturation, or that point at which no new themes emerge.[26]

Transcripts were coded following verification.[27] Three coders developed a coding framework that included both deductive categorical codes based on the interview guide (e.g., “barriers”) and inductive thematic codes (e.g., “mistrusting health system”). Coders independently applied the coding framework to the same interview transcript to resolve any differences in interpretation and ensure consistency in application of the codes. Once consistency was established, coders divided up the remaining transcripts.

Participants were aged 19–33, with most 20–24 years old. More participants were women than men, and most

TABLE 1 Summary of participants ($N = 23$).

	n	%
Age		
19	1	4
20–24	15	65
25–29	4	17
30–34	3	13
Gender/sex		
Woman/female	15	65
Donor	8	53
Nondonor	7	46
Man/male	8	35
Donor	4	50
Nondonor	4	50
Province		
Alberta	9	39
British Columbia	2	9
Ontario	7	30
Quebec	5	22
Blood donor history		
Donated/tried to donate	12	52
Never tried to donate	11	48

lived in Alberta and Ontario. The sample population was quite evenly split between participants who had donated blood or had tried to donate and those who had no experience with donation. By gender, participants were equitably split by donor status (see Table 1).

3 | RESULTS

Barriers to donation for young adults of African ancestry included macro-, mezzo-, and microlevel barriers (see Figure 1). Macro-level barriers refer to barriers at the level of systems and culture including social, political, and economic systems. Mezzo-level barriers refer to barriers at the level of organizational or institutional structures including formal and informal institutions. Interpersonal relationships are included in the mezzo-level since they involve people external to the individual. Microlevel barriers refer to barriers at the individual level; that is, barriers internal to the individual. Barriers identified by participants who had experience with donation and those who had never tried to donate blood were similar; however, results suggest some differences between the two groups in terms of relative significance of the different barriers. Results suggest that higher level barriers influence and may reinforce lower level barriers.

3.1 | Macro-level barriers

3.1.1 | Systemic racism and mistrust

Both donors and nondonors described systemic racism and mistrust of healthcare systems as barriers to donation with more nondonors identifying this as a systemic barrier than donors. One nondonor spoke about racism as a direct barrier to donation: “I'm probably gonna have to deal with some medical racism to go donate, and I don't always have the energy to do that” (23, F, nondonor). Participants who were donors described these barriers as reasons why family and community members did not donate blood.

Systemic racism and mistrust were grounded in personal experiences of racism in the healthcare system. Moreover, knowledge of mistreatment, exploitation, and racism in domains outside blood donation influenced participants', or their family and community members', views on and expectations of blood donation. For example, several participants described a general mistrust in their communities that donated blood might be used for scientific research and not given to a recipient. One nondonor explained that her parents did not donate because of mistrust:

> My parents are pretty well educated, … they know about HeLa cells and the Tuskegee syphilis trial… they just don't trust the scientific, the medical community specifically, I think, in terms of donations or any type of research. (24, F, nondonor).

3.1.2 | Sociocultural beliefs and views

Participants, both donors and nondonors, spoke about sociocultural beliefs about blood that evoked fear about what might be done with the blood. More donors than nondonors described sociocultural beliefs as a barrier in their communities “based on practices that happened back home” (20, M, donor). In sharing these views, participants were speaking of views held by elders or people in their community who had more recently come to Canada and not their own views. Several donors described being “part of a shift” (23, F, donor) in their community by talking to family members and elders about their own views on blood and donation.

Perceived stigma of SCD, informed by sociocultural views, was also identified as a barrier. Participants described a lack of open discussion about SCD in their families and communities, which some perceived as potential stigma, or “othering”

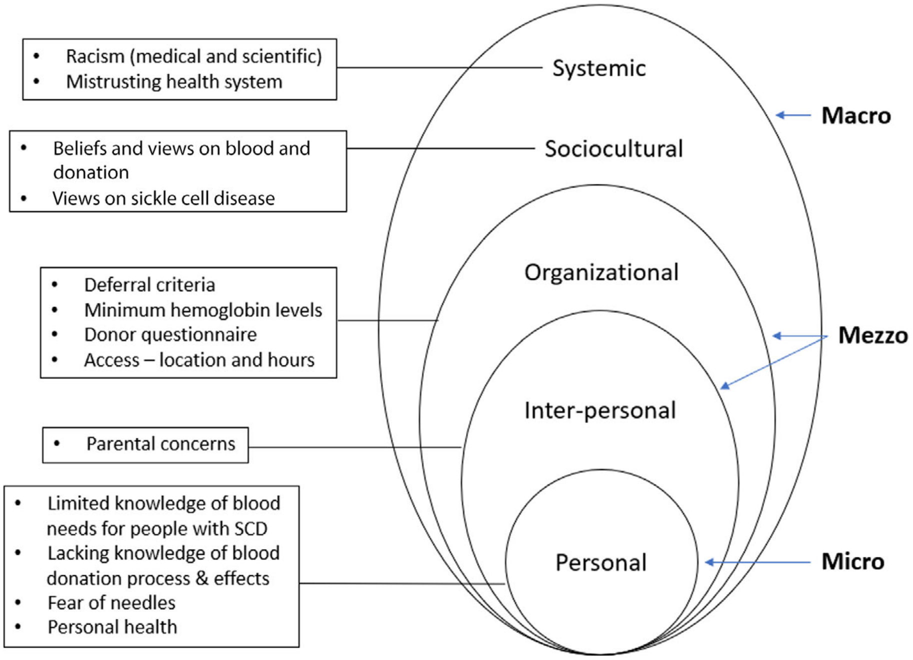

FIGURE 1 Socio-ecological model of barriers to donation. [Color figure can be viewed at wileyonlinelibrary.com]

(21, M, nondonor), of people with SCD. Others described a "shroud of secrecy when people have SCD" (20, M, donor). This "secrecy" led some participants to view SCD as something that should not be discussed.

3.2 | Mezzo-level barriers

3.2.1 | Deferral criteria and donor questionnaire

Deferral criteria and low hemoglobin were the most prevalent barriers for donors in our sample. Participants had been deferred from donating because of screening criteria including tattoos, piercings, malaria, COVID-19 temperature screening, and the former "MSM" (men-who-have-sex-with-men) criteria. Deferral due to low hemoglobin was the most prevalent screening barrier for donors with all but one participant identifying as a woman. Both donors and nondonors described a general awareness in their communities that many cannot donate because people of African ancestry have lower iron levels and therefore would be deferred.

Several nondonors described deferral criteria and minimum hemoglobin requirements as barriers because they viewed the criteria as exclusionary and disproportionately affecting Black people's ability to donate blood:

> Naturally lower iron levels in certain people makes them unqualified to donate blood. That just plays into this idea that European biological factors are the standard that everyone should conform to, which I think is part of medical racism" (20, F, nondonor).

One donor mentioned challenges with the donor questionnaire for people who speak English as an additional language. He had experienced this first-hand with his parent, who found the length and language of the questionnaire to be an obstacle.

3.2.2 | Limited access

Donors and nondonors described limited access to donor centers as a barrier. These included challenges with transportation, center hours, scheduling an appointment, and location of mobile donor events. Centers that were not easily accessible by public transportation and limited hours were the two most prevalent access barriers. Several donors described donating at donor events held at their university and having challenges accessing donor centers once they were no longer attending university.

3.2.3 | Parental concerns

Several donors in our sample described their parents as being concerned after learning that they had donated blood. Parental concerns included general discomfort with blood donation despite understanding the importance of blood for recipients, worry for their child's health after donating blood, and uncertainty about what donation involves and what is being done with the blood. These concerns were informed by their own experiences of mistrust in the healthcare system:

> My parents got mad at me for donating blood, like not me saving lives..., I think that much like [with] other medical things, they have concerns about it, ... what donating blood really is and where the blood is really going..., I understand their worry, I understand their lack of trust. (23, F, donor).

3.3 | Microlevel barriers

3.3.1 | Limited knowledge

Both donors and nondonors had limited knowledge about SCD and the need for people of similar ancestry to help meet the blood transfusion needs of people with SCD. While all participants had heard of SCD and more than half knew someone who had SCD, most participants did not know that blood donation from people of African ancestry was needed to increase the likelihood of a close blood-type match and better outcomes for SCD recipients. Several participants explained that learning this through their participation in this study increased their interest in donating blood.

Nondonors described lacking knowledge of the blood donation process—how blood is drawn, how donors are screened, and the physical effects of donating—as an obstacle to donation. One participant thought this lack of knowledge was, in part, due to insufficient content on blood donation in high school curricula. Without knowing how blood donation would affect their body, nondonor participants were uncertain of its physical toll.

3.3.2 | Fear of needles and health conditions

Participants described a fear of needles and their own health conditions as barriers to donating blood. For some nondonors, their health concerns were coupled with their limited knowledge of the physical impact of blood donation.

4 | DISCUSSION

Our study makes a unique contribution to the literature by focusing on barriers to donation for African, Caribbean, and Black young adults in Canada and by applying a socio-ecological model to understanding barriers. Our results show that barriers to donation for this population are multiple and multilevel. In addition to barriers such as lack of knowledge, medical racism and mistrust, fear of needles, deferrals, and sociocultural beliefs, which have been found in other studies,[8,13,15,17] for young adults, parental concerns were identified as a barrier. To our knowledge, parental concerns have not been previously reported in results. This novel finding may result from our focus on young adults and the relationships our participants have with their parents.

A socio-ecological framework enables us to conceptualize how barriers at different levels may interact and influence one another. For example, knowledge of systemic racism and mistrust (macro-level) influenced how nondonors viewed the deferral criteria (mezzo-level) and underlay parental concerns regarding blood donation (mezzo-level). Sociocultural beliefs and views about blood and SCD (macro-level) supported conditions that amplify the lack of knowledge of both blood donation and SCD transfusion needs (microlevel). Given the multilevel, interacting nature of barriers to donation, interventions aimed at addressing barriers must keep in view all levels when working to engage people from diverse Black communities. We suggest that given the influence of higher order, macro-level barriers, these warrant focused attention.

Systemic racism and mistrust in healthcare are macro-level barriers that go well beyond blood operators; however, blood operators would be well-advised to address these challenges to the extent possible. In North America, the sociopolitical awareness of anti-Black racism has been reignited with the tragic murder of George Floyd in 2020 galvanizing, once again, the Black Lives Matter movement, recognition of anti-Black racism as a social determinant of health[28] and increasing evidence of inequities in health and healthcare for Black communities.[29] This heightened sociopolitical awareness of systemic racism provides the context within which this study was conducted. While communities of African ancestry have had concerns with systemic racism and mistrust in blood donation for some time,[16] in the current context majority culture and structures are increasingly being called to account to address these inequities.

Addressing systemic racism and building trust in the blood system include tackling barriers, including deferral criteria, that disproportionately affect donors of African ancestry. Currently, in Canada, there is no licensed test for malaria, resulting in a lifetime deferral from whole blood donation for people who have ever had malaria. Advocates argue that a lifetime deferral for malaria, a treatable condition, is disproportionately severe when compared with shorter deferrals for other transfusion-transmissible infections. With regard to minimum hemoglobin levels, research shows that reference levels for hematologic markers including hemoglobin and hematocrit are lower for African-Americans than for White-Americans[30] supporting the view held by some participants that hemoglobin level requirements disproportionately exclude members in their community. As blood operators examine iron levels, ferritin testing, and supplementation to minimize health impacts on blood donors,[31–33] considering differences in reference levels across ancestral groups may facilitate more equitable criteria. While blood operators work to address deferral criteria, the call to donate blood from people of African ancestry must be balanced and transparent to ensure that communities are informed of deferral criteria that may prohibit or limit their participation. Building trust is critical to removing barriers to blood donation and would be enhanced by involving community members in the decision-making process. Patient advocacy groups such as SCDAC and SCFA have been advocating for more inclusive policies to increase blood donors of African ancestry.

Sociocultural beliefs and views about blood, donation, and SCD (macro-level) amplified the lack of knowledge about blood donation processes and the need for blood for people with SCD (microlevel). Blood holds significant social and symbolic meanings that are culturally and socially specific, with some views and beliefs more aligned with voluntary donation than others.[9] While studies have identified sociocultural views about blood and donation as a barrier,[34] our young adult participants did not personally hold these views but referred to elders and parents who did. Moreover, several participants who had donated saw themselves as addressing some of these sociocultural barriers by informing community members about blood donation. Results suggest that there may be differences in views and barriers across generations, including different migration generations (e.g., first-generation versus second-generation). It may be that more than age, migration generation may be a significant factor in differing views and would benefit from further study.

Results also suggest that sociocultural views on SCD (macro-level) that limit discussion of the disease support conditions that reinforce participants' limited knowledge of the need for blood for people with SCD (microlevel). Disclosing and discussing SCD is socially complex with social and healthcare implications for people with SCD and their families.[35] For example, disclosing may contribute to unwarranted attention and not necessarily lead to better healthcare.[36,37] This calls attention to the need for better healthcare and resources for people living with SCD at a systemic level. Trusted community leaders and SCD advocacy organizations may play an important role in increasing awareness of SCD and the need for blood donation from communities of African ancestry. Blood operators should work with community-based organizations to co-develop resources to support increased education and awareness in Black communities.

While our sample was nonrepresentative and not generalizable to the broader population of Black young adults, there were some differences across donor status and gender that suggest areas for further research. First, results suggest that mistrust of healthcare systems is a more significant barrier for nondonors than donors with more women than men expressing this as a barrier. Second, while donors reported less barriers at the microlevel than nondonors (e.g., lacking knowledge of blood donation and fear of needles), there was no indication of donor status effects at the mezzo-level (e.g., deferral criteria, donor questionnaire, low hemoglobin). Third, parental concerns were identified as a barrier for donors only, with these participants all identifying as women. It may be that parental concerns arise after learning of their child's donation; however, further research is needed to better understand the nature, emergence, and impact of concerns. Lastly, low hemoglobin was a barrier for many more women participants than men suggesting gender/sex effects.

4.1 | Limitations

Results from this study are based on young adults, living in a major urban city, and educated in Canada. While results suggest that migration history may be an important factor in understanding barriers to donation, we did not examine this explicitly. Moreover, we did not clarify the specific ethnicity of participants beyond confirming that they identify as African, Caribbean, or Black. Further research should explore these factors to better understand diversity within Black communities. Lastly, given that barriers may operate differently for nondonors than donors, additional research on nondonors is warranted.

ACKNOWLEDGMENTS

We would like to thank all the research participants and their invaluable contribution to this study. JH contributed to all aspects of this study and wrote, reviewed, and edited the manuscript; JW, BT, and JJ contributed to conceptualizing the project design and instruments, recruitment, data analysis, and reviewed and edited the manuscript; DD, HE-A, and PP contributed to project design and instruments, recruitment, and reviewed and edited the manuscript; UM and JR contributed to recruitment, data collection, data analysis, and reviewed and edited the manuscript. Thank you to all the Community Advisory Committee members who provided guidance throughout the research project. Thanks also to Canadian Blood Services' collaborators, and to Dr. Sophie Chargé and Dr. Gwen Clarke for their feedback on this manuscript.

FUNDING INFORMATION

This project was supported by a Social Sciences and Humanities Research Council (SSHRC) Partnership Engage Grant.

CONFLICT OF INTEREST STATEMENT

The authors have disclosed no conflicts of interest.

ORCID

Jennie Haw https://orcid.org/0000-0003-4009-5705

REFERENCES

1. SCDAC. https://sicklecelldiseasecanada.com/sickle-cell-anemia/
2. CDC. https://www.cdc.gov/malaria/about/faqs.html#print
3. Compernolle V, Chou ST, Tanael S, Savage W, Howard J, Josephson CD, et al. Red blood cell specifications for patients with hemoglobinopathies: a systematic review and guideline. Transfusion. 2018;58:1555–66.
4. Canada S. The Canadian census: a rich portrait of the country's religious and ethnocultural diversity. 2022.
5. Canada S. Diversity of the black population in Canada: an overview. 2019.
6. Dordunoo D, Abernethy P, Kayuni J, McConkey S, Aviles-G ML. Dismantling "race" in health research. Can J Nurs Res. 2022;54:239–45.
7. Khan AT, Gogarten SM, McHugh CP, Stilp AM, Sofer T, Bowers ML, et al. Recommendations on the use and reporting of race, ethnicity, and ancestry in genetic research: experiences from the NHLBI TOPMed program. Cell Genomics. 2022;2:100155.
8. Gahan L, Masser B, Mwangi C, Thorpe R, Davison T. Motivators, facilitators, and barriers to blood donation in Australia by people from ethnic minority groups: perspectives of sub-Saharan African, east/south-east Asian, and Melanesian/Polynesian blood donors. J Sociol. 2022;58:95–112.
9. Grassineau D, Papa K, Ducourneau A, Duboz P, Boëtsch G, Chiaroni J. Improving minority blood donation: anthropologic approach in a migrant community. Transfusion. 2007;47:402–9.
10. Klinkenberg EF, Fransen MP, de Kort W, Huis In't Veld EMJ, van Weert JCM. Unknown, so also unvalued? Blood donation awareness and attitudes of potential donors of Dutch and African descent. Vox Sang. 2021;116:513–23.
11. Klinkenberg EF, Huis In't Veld EMJ, de Wit PD, van Dongen A, Daams JG, de Kort W, et al. Blood donation barriers and facilitators of sub-Saharan African migrants and minorities in Western high-income countries: a systematic review of the literature. Transfus Med. 2019;29(Suppl 1):28–41.
12. Lallemand-Stempak JP. "what flows between us": blood donation and transfusion in the United States (nineteenth to twentieth centuries). Giving Blood: The Institutional Making of Altruism 2015: 21–35.
13. Polonsky MJ, Renzaho AM, Brijnath B. Barriers to blood donation in African communities in Australia: the role of home and host country culture and experience. Transfusion. 2011;51:1809–19.
14. Shaz BH, Demmons DG, Hillyer KL, Jones RE, Hillyer CD. Racial differences in motivators and barriers to blood donation among blood donors. Arch Pathol Lab Med. 2009;133:1444–7.
15. Spratling R, Lawrence RH. Facilitators and barriers to minority blood donations: a systematic review. Nurs Res. 2019;68:218–26.
16. Charbonneau J, Tran N. The paradoxical situation of blood donation in the Haitian-Quebec community. Can Ethnic Stud. 2015;47:67–92.
17. Tran NY, Charbonneau J, Valderrama-Benitez V. Blood donation practices, motivations and beliefs in Montreal's black communities: the modern gift under a new light. Ethn Health. 2013;18:508–29.
18. Alessandrini M, Carr A, Coghlan P. Building social capital through blood donation: the social futures project. ISBT Sci Ser. 2007;2:46–52.
19. Busby H. Trust, nostalgia and narrative accounts of blood banking in England in the 21st century. Health. 2010;14:369–82.
20. Smith A, Matthews R, Fiddler J. Recruitment and retention of blood donors in four Canadian cities: an analysis of the role of community and social networks. Transfusion. 2013;53(Suppl 5):180s–4s.
21. Oviedo P, Jaffré Y, Danic B, Mazières S, Chiaroni J. Impact of societal and legal context on the blood supply of African-ancestry populations in Western countries: a review of practices and the French example. Vox Sang. 2022;117:1137–44.
22. Bronfenbrenner U. Toward an experimental ecology of human development. Am Psychol. 1977;32:513–31.
23. White K, Ocampo M, Scarinci IC. A socio-ecological approach for examining factors related to contraceptive use among recent Latina immigrants in an emerging Latino state. Women Health. 2017;57:872–89.
24. Minkler M. Community-based research partnerships: challenges and opportunities. J Urban Health. 2005;82:ii3–ii12.
25. Viswanathan M, Ammerman A, Eng E, Garlehner G, Lohr KN, Griffith D, et al. Community-based participatory research: assessing the evidence. Evid Rep Technol Assess (Summ). 2004;(99):1–8.
26. Whittaker S. Qualitative research: what is it and how can it be applied to transfusion medicine research? Vox Sang. 2002;83(Suppl 1):251–60.
27. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101.
28. PHAC. Social determinants and inequities in health for black Canadians: a snapshot. 2020.
29. Miller YM, Butler-Foster T, Montemayor-Garcia C. Racial differences in transfusion practices: time to address structural racism. Transfusion. 2022;62:1471–6.
30. Beutler E, West C. Hematologic differences between African-Americans and whites: the roles of iron deficiency and alpha-thalassemia on hemoglobin levels and mean corpuscular volume. Blood. 2005;106:740–5.
31. Blake JT, O'Brien SF, Goldman M. The impact of donor ferritin testing on blood availability in Canada. Vox Sang. 2022;117:17–26.
32. Karregat J, Sweegers MG, Quee FA, Weekamp HH, Swinkels DW, Novotny VMJ, et al. Ferritin-guided iron supplementation in whole blood donors: optimal dosage, donor response, return and efficacy (FORTE)-a randomised controlled trial protocol. BMJ Open. 2022;12:e056316.

33. Zalpuri S, Romeijn B, Allara E, Goldman M, Kamel H, Gorlin J, et al. Variations in hemoglobin measurement and eligibility criteria across blood donation services are associated with differing low-hemoglobin deferral rates: a BEST collaborative study. Transfusion. 2020;60:544–52.
34. Charbonneau J, Daigneault S. Engaging ethnic minority blood donors. ISBT Sci Ser. 2016;11:140–7.
35. Bulgin D, Tanabe P, Jenerette C. Stigma of sickle cell disease: a systematic review. Issues Ment Health Nurs. 2018;39:675–86.
36. Benjamin R. Organized ambivalence: when sickle cell disease and stem cell research converge. Ethn Health. 2011;16:447–63.
37. Dyson SM, Atkin K, Culley LA, Dyson SE, Evans H, Rowley DT. Disclosure and sickle cell disorder: a mixed methods study of the young person with sickle cell at school. Soc Sci Med. 2010;70:2036–44.

How to cite this article: Haw J, Walrond J, Jayachandran J, Dordunoo D, Eche-Ameh H, Muwhen U, et al. Sickle cell disease and the need for blood: Barriers to donation for African, Caribbean, and Black young adults in Canada. Transfusion. 2023;63(7):1324–32. https://doi.org/10.1111/trf.17396