SICKLE CELL

JSCDH: JOURNAL OF SICKLE CELL DISEASE AND HEMOGLOBINOPATHIES

A Peer-Reviewed Journal Promoting Science, Clinical Care and Public Health in Sickle Cell Disease and Hemoglobinopathies.

ISSN: 2330-1473 DOI 10.14223

Volume VIII, Issue III
Publication date: October 1 2021

Guest Editor and 2021 Scientific Chair:
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Released in Association with The Foundation for Sickle Cell Disease Research's

INAUGURAL NURSING IN SICKLE CELL DISEASE SYMPOSIUM: ADVANCING THE SCIENCE OF SICKLE CELL DISEASE

A Message from our Guest Editor and 2021 Scientific Chair:
Coretta Jenerette, PhD, RN, AOCN, CNE, ANEF, FAAN

Nursing, like any other profession, is not a monolithic group. However, we are the most trusted profession. Trust may be because the agreed upon hallmark of nursing is caring. Caring includes providing care and caring in terms of kindness and concern for others who seek caregiving. In essence, individuals seeking care should expect empathetic practice from all healthcare providers, especially nurses, given our professional attributes. However, this is not the case for all patients.

When individuals with sickle cell seek care, they are often met with inappropriate labeling as drug-seeking for perceived non-existing pain or pain not consistent with their presentation. The label and subsequent treatment result in health-related stigmatization and potential poor outcomes, including inappropriate or delayed treatment. Nurses are often complicit in these interactions because nurses are often the first healthcare professional individuals with sickle cell encounter in the healthcare system, especially in the emergency department. For example, the triage nurse holds great responsibility in making sure that patients are assigned the appropriate triage level, driving the timeliness of care. We often hear about occasions when this does not happen as it should, based on evidence-based guidelines. Unfortunately, individuals living with sickle cell may not always experience the nurse who provides care and caring with empathetic practice.

In this issue of the Journal of Sickle Cell Disease and Hemoglobinopathies (JSCDH), we highlight the work of nurses who exemplify empathetic practice. This edition includes nurses contributing to improved outcomes in sickle cell from a global perspective. We all are human, despite the ways that some of us are treated. When one suffers, we all suffer.

Nursing goes beyond the call of providing care. Nurses also have the responsibility to advocate for patients. The American Nurses Association (ANA) states, “Nurses instinctively advocate for their patients, in their workplaces, and their communities; but legislative and political advocacy is no less important to advancing the profession and patient care.” Additionally, Healthy People 2030 focuses on the kind of health disparities and health inequities experienced by individuals living with sickle cell. Nurses providing direct care and nurse scientists can make a difference in eliminating these disparate outcomes. In this issue of JSCDH, you will see examples from nurses and others who have chosen to engage in empathetic practice and contribute to making the lives of individuals living with SCD better while “we” move toward a cure for sickle cell disease.

We thank all reviewers for sharing their time, knowledge and expertise with JSCDH’s authors in the evaluation of their work, without which it would be impossible to maintain the standards of our Journal.

Best,

Lanetta Bronté-Hall, MD, MPH, MSPH
Editor in Chief, President

Kyla Thorpe, MA
Chief Operating Officer

The Foundation for Sickle Cell Disease Research

TOP ABSTRACTS
ORAL PRESENTATIONS

Presenting: Friday, October 1, 2021 at 11:45 am

JSCDH-D-21-1106806

AN EDUCATION PROGRAM TO IMPROVE ACUTE NURSING CARE FOR PATIENTS WITH SICKLE CELL DISEASE

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Background: The Center for Excellence in Sickle Cell Disease (SCD) at Boston University/Boston Medical Center (BMC) is the largest in New England, treating over 500 patients. In June 2019, BMC convened a SCD Steering Committee in response to patient concerns to address gaps in care and problem areas. Nursing care was identified as one of the priority areas in the acute setting. Patients with SCD reported that nurses on the inpatient floors did not understand SCD and it complications and the need for supportive nursing interventions. We developed a nursing education curriculum focused on the management of vasoocclusive events (VOE's) and it complications with the goal of improving healthcare delivery in our patients.

Methods: Adult patients with SCD who attend our monthly sickle cell support group were asked a series of questions to identify areas of need for nursing education. We developed a training platform which combined didactic lectures and cases conducted using our simulation center to enhance nursing care. Lectures focused on the pathophysiology of SCD and its acute and chronic complications and nursing interventions which can enhance care and promote positive outcomes for hospitalized patients. We created a simulation curriculum consisting of two SCD case vignettes representing common complications of VOE: 1) Acute Chest Syndrome, and 2) fever/acute infection. Groups of no more than 6 nurses worked through the cases using simulation models that provided symptoms, physical exam findings and routine procedures. The education platform was piloted with Hematology/Oncology floor nurses and a 10 question post test was administered to asses knowledge acquired.

Results: The trainings were launched in the fall of 2019 and by October 2020 all fifty six nurses had completed the session. The COVID-19 pandemic delayed completion of the education pilot program by six months. All 56 nurses scored 90% or higher on the post-test. We used this pilot protocol to create a computer based module for annul recertification of nursing personnel.

Conclusion: Education surrounding SCD is essential to promote comprehensive nursing care in this patient population. Understanding the complexities of SCD and its complications is essential for monitoring sequelae, implementing nursing interventions, and providing support to promote positive outcomes in patients living with SCD.

VALIDATING SMOKING IN JAMAICAN ADULTS WITH SICKLE CELL DISEASE USING BIOCHEMICAL TESTS

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Background: Smoking in sickle cell disease is associated with ill-health and is sometimes under-reported. Validating smoking using biochemical methods is recommended to enhance scientific rigor.
Aim: A cross-sectional design was employed among 220 adults to validate self-reported tobacco and marijuana smoking using breath carbon monoxide (BCO) Breathalyzer (cutoff 6ppm), urine cotinine measures (cutoff 200ng/ml) and Tetrahydrocannabinol (THC) tests (cutoff 50ng/ml).

Methods: Setting and sample: This cross-sectional study recruited 220 adults who were conveniently sampled during their routine health maintenance visits at the Sickle Cell Unit (SCU) during May to July 2019. The clinic is an internationally recognized specialized centre that conducts research, education and provides treatment for persons with SCD, with over 5000 registered patients. Eligibility criteria included: 18 years old and diagnosed SCD. Exclusion criteria included: persons who were hearing impaired, had a major neurological condition such as cerebrovascular accidents (stroke), diagnosed learning disabilities, acute mental health or acute painful crises. These conditions would affect their ability to complete all aspects of the study. Ethical approvals were received from three Institutional Review Boards.

Survey Instruments: Data were collected using a socio-demographic instrument and the modified WHO Stepwise Approach to Chronic Disease Risk Factor Surveillance (STEPS) Instrument to assess smoking behaviour. The STEPS is a validated tool that has been used previously in Jamaica to assess lifestyle behaviours that are associated with chronic non-communicable diseases (33). All participants were asked if they smoked tobacco currently. If they said, 'yes' they were asked if they smoked daily or someday. The someday smokers were classified as occasional smokers. If they said 'no' they were then asked if they smoked in the past. Self-reported tobacco smokers were asked to indicate what form of cigarettes they used, whether it was manufactured, self-rolled cigarettes, vaped or others. Also, if they used smokeless tobacco such as snuff, chewed or other. Participants were also asked if they had environmental tobacco smoke exposure in their homes or workplace. A self-reported smoker (tobacco/marijuana) was operationally defined as an adult who has smoked 100 cigarettes/joints/spliff in his or her lifetime and who currently smokes (every day or some days). To assess marijuana smoking, eight (8) modified questions were added. Participants were asked if they currently smoked marijuana/ganja. If they responded 'yes', they were asked if they smoked daily or someday. Participants were also asked if they used marijuana in any other form or had environmental marijuana smoke exposure in their homes or workplace. Lastly, their reasons for smoking marijuana were assessed. The modified tool was pre-test among persons with SCD to assess face validity, understandability and ease of administration.

Procedure: Biochemical tests were performed using breath and urine samples. Breath carbon monoxide (BCO) was measured using the Bedfont handheld piCO-Smokerlyzer to measure expired CO after taking a deep breath. Each participant was allowed to do two breath samples, which was a slight modification to two previous studies (24, 28). Values with a standard deviation (SD±3) were recorded to assess the range, within a five (5) minutes interval. Only the first sample was analyzed for this paper as the second sample was consistently lower in most participants.

Urine analyses: Urine cotinine test was used to assess tobacco use and exposure. Each participant provided a urine sample which was tested using the NicoMeter®kit (http://www.accutest.net/products/ds81m1uh.php). The kit has a cut-off value of 200ng/ml and is easily administered and interpreted. It has a high reliability when compared to the ELISA and the Gold Standard, gas chromatography/mass spectrometry (GC-MS) (34). Marijuana smoking was assessed using the SD Bioline one step tetrahydronnabinol instant test kit (https://www.medicalexpo.com/prod/standard-diagnostics/product-70168-799917.html). This test is reliable and is used by the local National Council of Drug Abuse as the gold standard for assessing marijuana use and exposure. It is easily administered and has a cut-off value for cannabinoids of ≥50ng/ml which is widely used in the literature (31). Urine droplets were delivered to the medium and both tests were read within five (5) minutes as indicated by the manufacturers.

Data analysis: Data was analyzed using the Statistical Package for the Social Sciences version 20. Descriptive analyses included frequencies, mean and standard deviation. Inferential statistical included t-test, chi-square analysis was done for self-reported smoking and the biochemical tests, using the level of significance (p-value < 0.05). Determination of sensitivity and specificity was done for all biochemical tests. The test sensitivity is defined as the ability of the test to correctly identify those who have the outcome of interest (35). Tobacco smoking and marijuana were the outcome variables. The test would accurately identify the proportion of tobacco or marijuana users as having a positive urine cotinine test for nicotine, positive THC urine test for marijuana and BCO that is greater than 6 ppm if smoked either. These participants would be classified as true positives. The test specificity is defined as the ability of the test to correctly identify those who do not have the outcome of interest (35). Those persons would have a negative urine cotinine test for nicotine, negative THC urine test and BCO that is less than 7 ppm. These participants would be classified as true negatives. Assessment of the appropriateness of the test was done by calculating the positive predictive values (PPV) and negative predictive values (NPV). The PPV determined what percentage of persons who tested positive are actually smokers, while the NPV determined what percentage of the persons who tested negative are actually non-smokers (35).

Results: The mean age of the sample was (34.8 ±11.8 years). The majority 170 (77%) had homozygous S (HbSS) and were females 129 (58.6%). Self-reported tobacco smoking prevalence was 24/220 (10.9%), marijuana 23/220 (10.5%) and 33/220 (15%) smoked either product. Urine cotinine test sensitivity and specificity were (88.9% and 96%) respectively. Urine THC sensitivity and specificity were (66.7% and 94.6%). Breath carbon monoxide sensitivity and specificity were (17.9% and 94.2%) respectively, with mean BCO levels for smokers 'vs' non-smokers [13.6±7.9 ppm 'vs' 8.9±3.5 ppm; p=0.002]. Urine cotinine and THC had good negative predictive values (NPV) (99% and 97%) respectively, while BCO had a low NPV (26.2%) for assessing smoking.

Conclusion: Both urine cotinine and THC tests had good reliability in assessing smoking in sickle cell disease, but BCO did not.

Table 1. Self-reported tobacco smoking and cotinine test

Self-reported tobacco smoking	Cotinine Positive (n; %)	Cotinine Negative (n; %)	Total (n; %)
Smoke tobacco (Yes)	16 (88.9)	8 (4)	24 (10.9)
Smoke tobacco (No)	2 (11.1)	194 (96)	196 (89.1)
Count	18 (8.2)	202 (91.8)	220 (100)

Self-reported tobacco smoking and urine tests

Only 18/220 (8.2%) of the participants had a positive urine cotinine test. Comparison between self-reported tobacco smoking and urine cotinine tests: sensitivity and specificity (88.9% and 96%). This test identified 16/18 (88.9%) tobacco smokers had a positive urine cotinine result. These are the true positives. While it identified 194/202 (96%) of the non-tobacco smokers had a negative cotinine urine test result. These are the true negatives.

Table 2. Self-reported marijuana smoking and THC test

Self-reported Marijuana smoking	THC Positive Test (n; %)	THC Negative Test (n; %)	Total (n; %)
Smoke marijuana (Yes)	12 (66.7)	11 (5.4)	23 (10.5)
Smoke marijuana (No)	6 (33.3)	191 (94.6)	197 (89.5)
Count (n;%)	18 (8.2)	202 (91.8)	220 (100)

Self-reported marijuana smoking and urine test

Only 18/220 (8.2%) of the participants had a positive urine THC test. Self-reported marijuana smoking and urine THC had a sensitivity and specificity (66.7% and 94.6%). This test identified that 12/18 (66.7%) of marijuana smokers had positive urine tests. These are the true positives, while it identified 191/202 (94.6%) of the non-marijuana smokers had negative THC tests. These are the true negatives. One positive THC tester disclosed using marijuana sublingual medication for pain management, others used edibles and beauty products.

Table 3. Self-reported smoking and BCO levels

Smoking Statuses	BCO >6ppm (n; %)	BCO < 6 ppm (n; %)	Total (n; %)
Smoking :Yes	30 (17.9)	3 (5.8)	33 (15)
Smoking: No	138 (82.1)	49 (94.2)	187 (85)
Total (n; %)	168 (76)	52 (24)	220 (100)

Carbon monoxide levels for smokers and non-smokers

Smokers had significantly higher mean BCO when compared to non-smokers [13.63±7.88 ppm 'vs' 8.9±3.45 ppm; p=0.002]; 95% CI 10.8-16.4. Among the participants, 168/220 (76.4%) exceeded the 6 ppm cut-off level for smoking classification. Of the number that exceeding 6 ppm, 138/168 (82.1%) were non-smokers. Assessment of breath carbon monoxide (BCO) among the participants showed that males had a significantly higher BCO levels than females (11.02 ppm ±5.41 'vs' 8.6 ppm±3.85; p=< 0.001).

Comparison between smoking status and BCO: sensitivity and specificity was 17.9% and 94.2%, Fisher's exact p=0.043. This test identified that among participants that had exceeded the BCO cut-off value, 30/168 (17.9%) were smokers or true positives. It identified that the majority of those who had normal BCO, 49/52 (94.2%) were non-smokers or true negatives. **See Table 3**.

Table 4. Diagnostic abilities of biochemical tests

Test	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
Urine Cotinine	88.9	96.0	66.7	99.0
Urine THC	66.7	94.6	52.2	97.0
BCO	17.9	94.2	90.9	26.2

PPV: Positive Predictive Value; NPV: Negative Predictive Value

An examination of all three biochemical tests showed that urine cotinine and THC being the gold standard in this study for assessing tobacco and marijuana usage are reliable with the Negative Predictive Value (NPV) being 99% and 97% respectively. However, BCO had a low NPV (26.2%). Using cotinine urine test would predict a non-smoker with 99% accuracy, THC (97%), while BCO would identify a non-smoker with SCD with only 26% accuracy. **See Table 4.**

Table 5: Coordinates of the ROC Curve

BCO levels (ppm)	Sensitivity	1-Specificity
4.5	1.000	.904
6.5	.909	.738
8.5	.758	.508
10.5	.545	.332

Using the receiver operating characteristics (ROC) with a cut-off of 6 ppm, the area under the ROC (AUROC) was 0.7 (95% CI 0.60-0.79). Determining the cut-off values using the coordinates of the curve, there was an inverse relationship between BCO levels when compared with the sensitivity and 1-specificity. Using a low BCO cut-off value of 4.5 ppm would yield 100% sensitivity and 1-specificity of 90%. This would mean that all smokers (true positives) would be correctly identified, but 90% of non-smokers (false positive) would be classified as smokers. When the cut-off was increased to 6.5 ppm, sensitivity and specificity would be reduced to (91%) and 1-specificity (74%). This meant that 91% of the smokers (true positives) would be identified as smokers, however 74% of the non-smokers (false positives) would be identified as being a smoker. Since the mean BCO for the non-smokers in this study was 8.9 ppm, if a cut-off of 8.5 ppm was utilized, the sensitivity would be 76% (true positives) and 1-specificity 51% (false positives). Over half of the non-smokers would be misclassified as smokers. Using 10.5 ppm, sensitivity would be 55% (true positives) and 1-specificity 33% (false positives). **See Table 5.**

POSTERS

JSCDH-D-21-1119830

A QUALITATIVE STUDY OF THE EXPERIENCES OF PEDIATRIC PATIENTS RECEIVING VOXELOTOR

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Background: Sickle cell disease (SCD) describes a group of chronic, inherited blood disorders resulting from mutations that reduce or abolish normal beta globin production. The most common clinical manifestations of SCD are related to hemolytic anemia and vaso-occlusion, which can lead to acute and chronic pain and end-organ damage. Voxelotor is a first-in-class sickle hemoglobin–polymerization inhibitor, FDA approved for patients aged 12 years and older, that modulates hemoglobin's affinity for oxygen, prevents sickling of red blood cells, and possibly interrupts the molecular pathogenesis of the disease (Singh 2020). Its use is currently being investigated in patients aged 4 to 11 years. Incorporating the patient voice in drug development is becoming increasingly important to regulators, and collecting qualitative data directly from patient and caregiver insights alongside clinical data can aid in gaining a better understanding of meaningful treatment benefits in this patient population. The purpose of this study was to collect qualitative data to understand patient experiences with voxelotor, as reported by pediatric patients and their caregivers. Specifically, the study aimed to understand how the treatment affects symptoms and related impacts, as well as overall health-related quality of life.

Methods: This qualitative interview study involved interviews with children (aged 4-11 years) and their caregivers, recruited at 1 academic site in the United States. Eligible patients had been taking voxelotor for at least 4 weeks at the time of the interview. Concept elicitation interviews were conducted via telephone and a web conferencing platform (WebEx) by experienced qualitative researchers using a semi-structured interview guide. Interview transcripts were analyzed with MAXQDA qualitative data analysis software to allow for theme identification using an induction–abduction approach, which enabled the analysis to remain grounded in the data. Intercoder reliability was established early in the coding process by having two analysts independently code the same transcript. Patient enrollment will continue until analysis shows saturation and no new conceptual information is generated.

Results: This preliminary sample included 10 dyads representing 10 patients (7 female and 3 male) and their caregivers (7 female and 3 male); patients ranged in age from 6 to 11 years and had been taking voxelotor for a median duration of 18 months (ranging from 3 months to 3 years). Patients and caregivers discussed decreases in: frequency and/or severity of pain crises (n=5; 50%), fatigue (n=4; 40%), and presence of jaundice (n=4; 40%) since starting the treatment. In terms of effects on daily life, patients and their caregivers discussed improvements in ability to engage in activities such as swimming and other play (n=5; 50%). Among those reporting improvements in school (n=3; 30%), caregivers described patients' increased focus, fewer absences, and increased participation. Most of the sample also cited improvements in health-related quality of life, most notably including a general feeling of improved quality of life (n=8; 80%).

Conclusions: This is the first study that reports on qualitative experiences of pediatric patients being treated with voxelotor. Almost all patients experienced improvements in health-related quality of life after initiating therapy with voxelotor, highlighting the utility and potential benefit of voxelotor in the pediatric SCD population. These findings should aid in the design of post-marketing surveillance trials that require SCD-specific patient-reported outcome measures.

JSCDH-D-21-1115737

EVALUATION OF POINT OF CARE TESTS FOR SICKLE CELL ANEMIA IN LUANDA, ANGOLA

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Background: Sickle cell disease (SCD) is among the most common, lethal and poorly recognized diseases globally. In high-resource countries, early identification of SCD through newborn screening (NBS) is routine and subsequent delivery of preventive measures and comprehensive care is highly effective in reducing morbidity and early mortality. In lower-resource settings, where the incidence of SCD is much higher, NBS is limited to only a few pilot programs. Despite the proven efficacy of NBS, large-scale implementation remains infeasible in many sub-Saharan countries due to inadequate financial, laboratory, and technical resources. The development and deployment of low-cost, rapid, user-friendly, and accurate diagnostic testing for SCD is imperative.

There are two promising point-of-care (POC) tests (SickleSCAN and HemoTypeSC) that may allow for a simplified approach to newborn screening for SCD. There have been few real-world studies that compare these tests head to head, and none of these studies evaluated the healthcare staff on user-friendliness. The WHO has developed ASSURED Criteria for the ideal characteristics of a POC test in resource-limited settings. The "U" in ASSURED stands for "user-friendly" with a statement that POC tests should be simple to perform and require minimal training. For these reasons, it is essential to evaluate the user experience when considering the utility and applicability of each of these novel diagnostic tests. We performed a study in Luanda, Angola to evaluate the real-world implementation of these POC tests in maternity and immunization centers to gain better understanding of their feasibility and user preference.

Methods: The study was a prospective evaluation of two rapid, POC tests (SickleSCAN or HemoTypeSC) in Luanda, Angola. To evaluate the real-world feasibility and accuracy, with the guidance of the Angolan Ministry of Health, we selected 10 sites, including both birth hospitals and vaccination sites, to screen infants < 6 months of age. The study was designed to mimic a real-world setting with all POC testing performed and interpreted by local healthcare staff (nurses, nursing students, and laboratory technicians) with basic instructions as to the use of each test. In effort to evaluate usability, we solicited objective and subjective feedback from the healthcare staff who performed and interpreted the POC test results using an anonymous paper-based survey. The survey included five Likerk-scale questions assessing the difficulty in performing and interpreting the tests along with if the healthcare staff felt the tests could be easily incorporated into their daily workflow. The survey was developed by the study team nurse and translated into the local language of Portuguese.

Results: In total 100 healthcare staff (nurses, technicians, nursing students, and doctors) participated in the study and completed the survey. 82% of staff from all site's said they had no difficulty performing the HemoTypeSC tests and 66% said they had no difficulty performing the SickleSCAN test. 70% said they had no difficulty interpreting the results of the HemoTypeSC and 75% said they had no difficulty interpreting the SickleSCAN results. 84% of staff from all sites felt the HemoTypeSC could be easily incorporated into their daily workflow and 98% felt

the same about the Sickle SCAN. See Table 1 for additional comments by the healthcare staff.

63% of the tests were performed in maternity wards at the time/day of birth and 37% were performed in immunization centers. 48.5% of the tests were performed by nurses, 30.5% by nursing students, 20.8% by technicians, and 0.2% by doctors. The SickleSCAN took an average of 7 minutes to run, was repeated 2 times (0.2%) due to invalid results, and read wrong by the healthcare staff 11 times (1.1%). The HemoTypeSC took an average of 15 minutes to run, was repeated 68 times (6.8%) due to invalid results, and was read wrong by the healthcare staff 4 times (0.4%).

Conclusions: This study demonstrates the feasibility and user-friendliness of both HemoTypeSC and SickleSCAN for diagnosing SCD in newborns in a limited-resource setting of Luanda, Angola. This study also demonstrates the importance of obtaining feedback and buy-in from the healthcare staff prior to the implementation of new programs. Sickle SCAN was preferred by local staff likely due to the shorter time to interpretation and reduced need for repeating the test. Further implementation studies are needed to determine the appropriate strategy for these POC tests in low-resource setting of sub-Saharan Africa.

Table 1. Additional Comments Regarding the Feasibility and Implementation of POC tests for Sickle Cell Disease (Responses *Translated from Portuguese to English)*

Positive Comments	Negative Comments
- "It was very good, and a quick test (SickleSCAN) and practice, I liked it very much."- *Nurse* - "I liked the implementation of the rapid tests, because it will help diagnose the disease of sickle cell anemia."- Nurse - "Quick test (Hemotype) of easy interpretation liked and will be very useful for the life and development of the child."- *Technician* - "The test (SickleSCAN) is practical and very objective in its realization. And I think it could be part of the work routine."- *Technician*	-"I don't think it (Hemotype) will be embedded in my workflow because it's important by the time of interpretation of the result."- *Nurse* - "Testing (Hemotype) and feasible but delays the work of technicians."-*Technician*

JSCDH-D-21-1120177

FACTORS PREDICTIVE OF REPRODUCTIVE INTENT IN PERSONS WITH SICKLE CELL DISEASE OR TRAIT

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Background: There are reproductive complications associated with sickle cell disease (SCD) in both men and women afflicted with SCD. Yet, evidence is scarce about predictors of the intent of persons with SCD or sickle cell trait (SCT) to become a parent. This understanding will be useful in guiding future health discussions of reproductive options for persons with SCD or SCT. The study purpose was to examine sociodemographic factors that predict the intent of persons with SCD or SCT to become a parent.

Methods: This study was a cross-sectional exploratory analysis of baseline data of a randomized controlled trial comparing CHOICES intervention to usual care. CHOICES is a web-based multimedia educational intervention designed to help persons with SCD or SCT implement an informed reproductive plan. Participant's recruitment occurred in multiple settings (e.g., pediatric and adult sickle cell clinics, public settings, and online). Data were collected at locations of participant's choice. Participants (**N=234** [138 with SCD; 96 with SCT], mean age 25.9 years, 65% female and 94% African American) completed baseline measures that included reproductive knowledge, behavior, and intention using Sickle Cell Reproductive Health Knowledge Parenting Intent Questionnaire that has been validated in persons with SCD or SCT. We recorded the primary outcome "likely to become a parent", or if the participant already was a parent "likely to become a parent again" on a 0-4 scale where 0 means "not at all likely" and 4 means "extremely" likely. Descriptive and correlational statistics using statistical software R were used for this analysis.

Results: The results showed that sickle cell genotype (p< .001), employment (p=.001), and insurance (p=.03) were significant predictors of intent to become a parent (again) among participants with no or one child. Whereas influenced by others predicted the intent to become a parent (again) in both persons with at most one child (p=.001) and participants with two or more children (p=.001).

Conclusions: Findings indicate that a set of factors predicted the intent to become a parent among SCD or SCT persons with no or one child and those with at least two children. Findings indicate the importance of additional research to gain an in-depth understanding of the extent to which the sociodemographic factors influence intent to become parents in persons with SCD or SCT to develop educational interventions about reproductive decision-making for persons with SCD or SCT.

		0 or 1Child			2+ Children		
Variable	**Category**	***n***	**Mean ± SD**	***p***	***n***	**Mean ± SD**	***p***
Sickle cell genotype	SCT	56	2.89 ± 0.93	<.001	40	1.79 ± 1.19	.92
	SCD (SS)	80	2.18 ± 1.07		23	1.70 ± 1.22	
	Other SCD	33	2.52 ± 0.97		2	2.00 ± 1.41	
Education	High School	50	2.50 ± 1.07	.20	28	1.78 (1.34)	.42
	Some College	84	2.36 ± 1.09		30	1.63 (1.13)	
	College or higher	35	2.74 ± 0.89		7	2.33 (0.52)	
Employment	Student	28	2.75 ± 0.97	.001	6	1.83 ± 1.33	.42
	Employed	62	2.76 ± 0.95		25	1.52 ± 1.08	
	Unemployed	77	2.17 ± 1.08		32	1.94 ± 1.24	
Insurance	Yes	143	2.41 ± 1.05	.03	55	1.76 ±1.19	.43
	No	23	2.91 ± 1.00		6	2.17 ±1.17	
Variable	**Mean ± SD / Median**		**Correlation**	***p***	**Mean ± SD / Median**	**Correlation**	***p***
Age	24.9 ± 4.9		-0.15	.05	28.5 ± 3.8	0.01	.95
Income	10k-20k		0.13	.11	10k-20k	0.15	.23
Influenced by others	1.03 ± 1.06		0.19	.01	0.52 ± 0.93	0.33	.01

Table 1: Predictors of the Intent to become a parent among persons with 0-1 child and 2+ children

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Background: Manifestations of sickle cell disease (SCD) include symptoms (e.g., pain), that begin in childhood and may occur daily. Symptom management often begins at home, requiring tools for developing self-management strategies in the everyday, real-world setting. The purpose of this study was to test the feasibility of Voice Crisis Alert V2, a self-management intervention (application; app) for youth with SCD in the context of transition from parent-led management to youth self-management.

Methods: Feasibility testing was guided by the RE-AIM(**R**each, **E**fficacy, **A**doption, **I**mplementation, **M**ai ntenance) framework with single-group pre-post intervention design. Participants were 30 dyads of children/adolescents 11 – 17 years and the parent/caregiver, and 15 young adults (YA) 18 – 25 years recruited from a SCD clinic in the Southeastern US. Data were collected on app use, by survey of youth or caregivers at 4 time points [baseline, 6 weeks (mid-intervention), 12 weeks (end-of-intervention), 24 weeks (3-months post-intervention)], and by post-intervention interviews. Outcomes included symptoms (e.g., pain, fatigue), health-related quality of life, transition readiness, and app usability (at 12 weeks). App usability was assessed using the mHealth App Usability Questionnaire (MAUQ); Likert responses range from 1 (strongly disagree) to 7 (strongly agree) with higher mean scores indicating higher usability. Analyses of feasibility data were conducted using descriptive statistics. Intervention components are described in Table 1.

Results: Key demographic characteristics of children/adolescents and YA are in Table 2. Caregivers (n = 30) were a mean 42.6 years, 100% female, 93% Black, and 90% mothers of the child/adolescent. Recruitment rates were approximately 2 dyads/week and 4 YA/week. Of those approached for study participation, 86% dyads and 89% YA expressed interest. All who expressed interest met eligibility criteria and enrolled. Retention rates for dyads were: 97% at baseline, 83% at 6 weeks, 87% at 12 weeks, and 80% at 24 weeks. YA were retained at 100% for each time point. Overall, participants completed 1856 actions within the app (dyads: 1246, YA: 610). App use was broken down by timeframe as follows: baseline – 6 weeks, 6 weeks – 12 weeks, 12 weeks – 24 weeks, and after 24 weeks. Most app actions occurred from baseline – 6 weeks (dyads: 65%, YA: 67%), followed by 12 weeks – 24 weeks (dyads: 16%, YA: 15%). The "I'm in Pain" app component was the most frequently used across all timeframes in both groups. Five dyad participants did not use the app; of these, 1 was lost to follow up at baseline, 2 were lost to follow up at 6 weeks, and 2 completed study visits but did not use the app. Three YA did not use the app. Table 3 presents app use by component and study timeframe. Mean, median MAUQ scores were similar for children/adolescents (5.5, 5.7), caregivers (5.5, 5.6), and YA (5.4, 5.9), and indicated good usability.

Conclusions: Findings support feasibility of the intervention and study procedures in both youth/caregiver dyads and YA. Analysis of outcomes data and correlations with app use will be conducted to determine the preliminary impact of the intervention along with analysis of post-intervention interviews to inform a future effectiveness trial.

Name	Activities	Self-management strategy
Crisis Care	Documentation of health history including medication adherence and tracking	Disease-specific care
I'm in Pain	Documentation of pain (ecological momentary assessment) using a customizable avatar to record pain, pain characteristics, and associated symptoms	Symptom monitoring, disease-specific care
Pain History	Customizable calendar with chart that displays history of documented pain and pain characteristics	Symptom monitoring and tracking
My Chart	Link to the My Chart app to send secure messages to provider(s)	Communication with healthcare provider
Sickle Cell Information	Targeted educational information on various aspects of SCD, including transition and resources for transition	Knowledge and information about disease and care

Table 1. Intervention components

Variable	Participant Group	
	Children/Adolescents (*n* = 30)	Young Adults (*n* = 15)
Age (years), mean (*SD*)	13.8 (4.7)	20.0 (2.1)
Gender, Female, n (%)	14 (47)	9 (60)
Race, n (%)		
African American/Black	29 (97)	15 (100)
Other	1 (3)	0
Type SCD, n (%)		
HbSS	15 (50)	4 (27)
HbSC	9 (30)	9 (60)
Sickle Beta Thalassemia 0	1 (3)	1 (7)
Sickle Beta Thalassemia +	1 (3)	1 (6)
Other/don't know	5 (13)	0
Insurance		
Medicare/Medicaid	12 (40)	10 (67)
Private	10 (33)	2 (13)
Other/other public	2 (7)	1 (7)
None	3 (10)	0
Prefer not to say	3 (10)	1 (7)
Number ED visits for SCD painful event (past 6 mo), n (%)		
0	18 (60)	4 (27)
1 – 3	11 (40)	7 (46)
4 or more	0	4 (27)
Number hospitalizations for SCD painful event (past 12 mo), n (%)		
0	19 (65)	4 (27)
1 – 3	8 (28)	8 (53)
4 or more	2 (7)	3 (20)

Table 2. Participant demographics by group

	Crisis Care n (%)	I'm in Pain n (%)	My Chart n (%)	Pain History n (%)	Settings n (%)	Sickle Cell Information n (%)
Baseline – 6 weeks	18 (72)[a] 10 (83)[b]	24 (96)[a] 12 (100)[b]	15 (60)[a] 7 (58)[b]	24 (96)[a] 11 (92)[b]	20 (80)[a] 10 (83)[b]	21 (84)[a] 12 (100)[b]
6 weeks – 12 weeks	5 (20)[a] 2 (17)[b]	16 (64)[a] 8 (67)[b]	2 (8)[a] 1 (8)[b]	8 (32)[a] 3 (25)[b]	3 (12)[a] 1 (8)[b]	7 (28)[a] 1 (8)[b]
12 weeks – 24 weeks	4 (16)[a] 3 (25)[b]	12 (48)[a] 2 (17)[b]	5 (20)[a] 0[b]	8 (32)[a] 4 (33)[b]	3 (12)[a] 2 (17)[b]	6 (24)[a] 3 (25)[b]
Past 24 weeks	1 (4)[a] 1 (8)[b]	4 (16)[a] 1 (8)[b]	1 (4)[a] 1 (8)[b]	1 (4)[a] 1 (8)[b]	1 (4)[a] 1 (8)[b]	1 (4)[a] 1 (8)[b]

Table 3. Number and percent of dyad and YA use by app component and timeframe

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Background: The 2014 National Heart, Lung, and Blood Institute (NHLBI) evidence-based guidelines recommend acute pain management for patients with SCD include triage as high priority (Emergency Severity Index (ESI) 2) when the initial pain score was ≥ 7; initial opioid analgesic administration within 30 minutes of completion of triage or 60 minutes of arrival to the ED; time to re-administration of a second opioid within 15-30 minutes of the first; and admission for pain not managed within 6 hours of arrival to the ED. To our knowledge, current research has not fully described objective clinical and demographic characteristics of patients with SCD who experience delays in evidence-based pain management in the ED. Thus, the objectives of this study were to describe the clinical and demographic characteristics of adult patients with SCD who visited the ED, determine overall guideline adherence, and measure differences in characteristics to guideline adherence with a focus on timeliness-to-initial opioid administration.

Methods: We conducted a retrospective medical record review on all ED visits for adult patients with SCD between January 1, 2015, and December 31, 2015, in which the chief complaint was pain-related, the patient received an initial evaluation for complications during triage, the initial pain score was ≥ 7, and the patient had a discharge diagnosis that included the term “sickle cell.” Patient demographic and clinical characteristics were extracted from the electronic health record along with visit characteristics. Characteristics were compared to overall adherence to guidelines and for time-to-initial opioid administration.

Results: A total of 438 visits for 108 individual patients with SCD were included in the analyses. No visits adhered to all of the NHLBI guidelines. Ten visits were triaged as an ESI Level 2. The average time-to-initial IV opioid was 85 minutes. Although 24% (n=105) of visits were adherent to time-to-initial opioid administration guidelines, there were significantly more visits nonadherent to the guidelines for time-to-initial administration of an IV opioid (n=333, 76%, $p < .001$). Time-to-second opioid administration (≤ 30 from the first administration) was not significant between visits that were adherent to the guideline vs. those that were nonadherent. Seven of the 56 visits resulting in admission were adherent to the guideline for admission in ≤ 6 hours, whereas 17 were not.

Conclusions: There is a significant delay in time-to-initial IV opioid administration and overall adherence to NHLBI guidelines for acute pain management in adult patients with SCD. No significant differences in patient-level demographic or clinical variables were observed when guideline adherence was compared. Further investigation is warranted to determine factors that inhibit adherence to evidence-based guidelines in the care of individuals with SCD in emergency departments. Guideline-based care could improve health outcomes and the care-seeking experience for this vulnerable, underserved population.

JSCDH-D-21-1120460

MAPPING TRANSITION IN SICKLE CELL DISEASE TO MELEIS' TRANSITIONS THEORY: A SCOPING REVIEW

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Background: As advances in sickle cell disease management have increased life expectancy, the transition from pediatric to adult healthcare has become increasingly common and challenging. As a result, the need for theory-based transition programs is vitally important. Meleis' Transitions Theory addresses key constructs that can inform the development and evaluation of transition interventions for maturing pediatric patients with sickle cell disease. Guided by constructs of Meleis' Transitions Theory, the purpose of this scoping review was to examine the literature on sickle cell transition of care (ToC) in the United States to 1) map transition practices to theory constructs and 2) identify theory-informed gaps in practice that could lead to the suboptimal ToC.

Methods: The Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Scoping Reviews (PRISMA-ScR) guided the conduct and reporting of this review.

To be considered eligible to be included in the review, all articles had to focus on the process of transition for people with SCD. The transition process could include pre-, during, and post-transition but could be about post-transition without mentioning the process. SCD could include any form of the disease such as sickle cell anemia, sickle beta-thalassemia, sickle beta-plus thalassemia, and sickle hemoglobin-C disease. The articles had to be published in the past 10 years (2011 – 2021), written in English, and focus on patients in the United States due to the unique healthcare and public health insurance characteristics. The search strategy was curated with the help of a health sciences librarian and used for identifying articles. Databases included PubMed and CINAHL due to their comprehensive selection and focus on health science research. The initial search between the databases produced 302 articles (PubMed: 196 and CINAHL: 106) screened for duplicates through EndNote Web. Ninety-five duplicate articles were removed, leaving 207 articles screened for eligibility based on titles and abstracts. One hundred twelve articles were excluded resulting in 95 full-text articles to assess for further eligibility. Of the final review, 44 full-text articles were excluded based on not obtaining the full-text, not focusing on patients within the U.S., focusing on post-transition only, or having a primary focus on other genetic diseases (e.g., cystic fibrosis). In the end, 51 studies were deemed eligible and included in the review. Articles selected for inclusion were aggregated into a table, labeling them by year published and article title. Then they were organized by relevant constructs of the Transitions Theory. These columns identified Meleis' constructs such as the types of transition triggers (developmental, situational, health and illness, and organizational) and intervention methods (clarification, identification of milestones, mobilization of support, and debriefing). The goal is to map the literature on ToC in SCD to Meleis' theory to identify key transition concepts being used and gaps that may inhibit transition of care success.

Results: Of the included 51 final articles, 36 (71%) were primary research articles consisting of qualitative, quantitative, and case study approaches. The remaining 15 of the 51 (29%) articles were secondary or non-research articles were literature reviews, commentaries, and opinion articles. Twenty (39%) articles described ToC based on developmental readiness, while 8 (16%) articles described ToC based on age only. Six (12%) highlighted situational

circumstances such as pregnancy, incarceration, transition to college, and sudden changes in insurance being used to trigger ToC. Three (6%) highlighted organizational transition triggers such as unique transition program aspects or policy changes. The final three (6%) addressed health-illness transitions being triggered by severe cases of neurocognitive defects or other severe or chronic illnesses that adult specialists could manage more effectively.

Conclusions: The purpose of this scoping review was to provide an overview of transition programs and highlight the discrepancies in the transition to adulthood for people with SCD regarding the use of Transitions Theory. This review revealed gaps in ToC in SCD. There has been an effort to streamline ToC in some SCD programs. However, they are still not as connected as they should be because there is not a formal evidence-based theoretical framework consistently used to guide ToC in SCD. This has resulted in significant differences between policies and operations, such as some SCD patients being pushed to transfer at a certain age, rather than transition based on appropriate theory-based rationale.

JSCDH-D-21-1119812

PARENTS PLANS REPORTED BY YOUNG ADULTS WITH SICKLE CELL DISEASE OR SICKLE CELL TRAIT

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Background: There is scant research evidence about the parenting plans of young adults with sickle cell disease (SCD) or sickle cell trait (SCT). The purpose of this study was to evaluate the variation and accuracy of parenting plans of individuals with SCD or SCT in child bearing age.

Methods: We analyzed parenting plans data from participants in the experimental group of a randomized controlled trial (RCT). Participants (N= 114, mean age 26±5 years, 90% Black, 62% female, 38% male, 83% never married, 59% diagnosed with SCD, and 41% with SCT) completed the valid and reliable internet-based SCKnowIQ questionnaire, which measures the outcomes of the RCT and participants' preferences about being a parent. We created a computerized algorithm using participants' responses about parenting preferences and their partner's sickle cell status to generate tailored parenting plans for them.

Results: The computerized algorithm generated 31 different parenting plan versions to accommodate the variety in the participants' responses. For participants with SCD, we generated a parenting plan version for 16 participants who wanted to be parents, had no partner, were not likely to be pregnant, and wanted their child to be free of SCD. For participants with SCT, we generated a parenting plan version for 6 participants who wanted to be a parent, had a partner with SCT, were not likely to be pregnant, and wanted their child to be free of SCD. Of the participants, more than half required modification in their reproductive behavior to accomplish their goals of becoming a parent. Approximately, 10% reported that the computer-generated parenting plans were not accurate or had flaws in logic.

Conclusions: Findings provide insights into the variety and accuracy of parenting plans generated by computer algorithm. Future work is needed to further guide refinement of the algorithm to produce a more accurate, patient-centered, tailored parenting plans for young adults with SCD or SCT.

JSCDH-D-21-1106740

SICKLE CELL DISEASE: BLOOD AND TISSUE DONATION FROM LIFE-LONG BLACK DONORS WILL HELP

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ABSTRACT: Sickle Cell Disease (SCD) is a monogenic autosomal recessive blood disorder that affects a significant number of predominantly ethnic Canadians. This cultural-sociological study sought to identify core determinants that influence blood and tissue donation among the Non-White population within the 18–35-year age cohort, in Edmonton, Alberta, Canada. Researchers collected data through non-probability sampling methods from individuals within various localethnic minority communities (n= 104). The sample was administered a survey that measured determinants of blood and tissue donation. The research design consisted of a pretest questionnaire, a stimulus (video of apheresis treatment), and a posttest questionnaire. The research findings reflect a need for educational tools pertaining to blood and tissue donation and well-crafted and targeted blood donation messages, that concentrate on addressing the ethnic minority prospective donor population- in specific the African Canadian population in Edmonton, Alberta.

Keywords: blood and tissue donation, ethnic minorities, determinants of donation, blood donation culture

Determinants of Blood and Tissue Donation Among the Non-White Population

Ethnic minorities are disproportionately affected by sickle cell disease (SCD) (Spratling and Lawrence 2019), while also being a population generally lacking in the blood donation practice within developed countries (Makin et al. 2019), and as essential methods of treatment for SCD (such as blood transfusions, hematopoietic stem cell transplantation (HSCT), etc.) require donors, there is an essential problem to address. Namely that without sufficient diversity in the donor population, the SCD patient population will be adversely affected. The basis of the issue is summed up in the following quote:

Broader racial/ethnic representation in the donor pool is necessary from an operational standpoint to ensure sustainability of a diverse blood supply, as broad racial/ethnic representation has important consequences regarding antigen-negative blood utilization and availability. (Shaz BH et al. 2008; Shaz BH and Hillyer CD,2010, as cited in Patel et al. 2019:2904-2905).

The preceding notion is not only true for the blood supply, but of the stem cell supply as well. There must be an adequate representation of ethnic minorities in the hematopoietic stem cell (HSC) donor community to satisfy and balance the needs of patients requiring HSCT, which includes donors of umbilical cord blood (UBC), bone marrow (BM), and peripheral blood (PB), and these donors must be suitably matched, phenotypically, to the recipients; thus requiring a donor population of various ethnicities consisting of diverse phenotypes, to support the recipient population. Regarding these issues of donation, there is cause to place attention on the ethnic minority communities' determinants of blood and tissue donation. Therefore, the current research sought to identify and investigate various determinants that may potentially play a significant role in donation. The fundamental rationale behind such an endeavour lies in the notion that with accurate knowledge regarding a set of behaviours and attitudes, beneficial change can be encouraged that will strengthen the well-being and health of the larger community. This research is rooted in the tradition of

'applied research', which seeks "investigations directed more towards insights that allow us to live more efficiently and effectively." (Babbie, Roberts, and Edgerton 2021:498). Therefore, a primary objective of this study is to produce knowledge that will inform the proper facilitation of an effective and efficient 'blood donation culture', that seeks to foster a sense of community cohesion, altruism, and obligation focused on aiding individuals suffering from malignancies that may be healed by treatments relying upon donation. To accomplish said objective, this quantitative research study investigated the determinants that are likely to motivate or deter individuals from donating blood or tissue products, and the role these determinants play in regular blood/tissue donation in individuals between the ages of 18-35 (who are specifically sought after, as they have the potential to become lifelong donors).

BACKGROUND The donor pool of any given country must be adequately diverse to provide accessibility to a vast array of necessary "substances of human origin (SoHo)" (Huis in 't Veld, de Kort, and Merz 2019:1273) (e.g., blood products, UCB, or BM), the under-representation of ethnic minorities in this pool may be harmful to the health of many individuals who heavily rely on the adequacy of the healthcare system. This lack in ethnic minority donors is deeply problematic, asdiseases such as SCD and thalassaemia require frequent support from the donor population and are recurrently found in ethnic communities. An example: "SCD occurs in about 1 in every 500 African American (AA) births, 1 in every 36,000 Hispanic-American births, and 1 in every 100,000 Caucasian births" (Hassell 2010, as cited in Spratling & Lawrence2019:218).

SCD is deemed to be one of, if not the most, common inherited monogenic blood disorders, which currently affects at least 100,000 Americans and, moving beyond the one nation, millions more throughout the rest of the world (Park and Bao 2021; Pavan and dos Santos 2021). SCD and thalassemia affect ethnic minority populations in greater proportion in the USA, then non-ethnic minorities (Spratling and Lawrence 2019), which is largely found to be the case in Canada as well. Although, unfortunately, the exact quantity of individuals living with SCD in Canada is not definitively known (Morin, Skeate, and Clarke 2020). However, being that the Canadian context consists of an eclectic ethnic population with more than 250 ethnic origins being reported in the Canadian population in 2016 (Statistics Canada 2016), there is cause to believe the disease prevalence in the country is significant.

The SCD population in Canada -and abroad- experience the brunt of a difficult disease, for example: adults who are suffering from SCD are likely to endure organ dysfunction that drastically affects their existence and quality of life, which can often culminate in early death (de la Fuente et al. 2019; Tozatto-Maio et al. 2020). Additionally, patients with SCD contend with symptoms such as: chronic anemia, lung and heart injury, chronic inflammatory process, bone infarcts, etc. (Pavan and dos Santos 2021); and other risks inherent to the disease such as chronic hemolysis, vasculopathy, as well as consequences of the condition that may result in increased rates of unemployment and disability (Brodsky and DeBaun, 2020).

The chronic and painful nature of SCD requires individuals to seek out medicinal treatments. These treatments, however, are limited in their number and in their effect. There is currently one curative therapy that demonstrates significant results in sufficiently and persistently quelling the effects of SCD, this is HSCT (Park and Bao 2021); the stem cells required for transplantation are commonly derived from BM, UCB, and PB (de la Fuente et al. 2019; Haw et al. 2019; Park and Bao 2021). More commonly used treatments include: blood transfusions, and medications; of which only four are FDA approved: hydroxyurea, L-glutamine, crizanlizumab, voxelotor, the latter three were only approved in the last three years, which points to the improvement and development in the variety of SCD treatment options (Park & Bao, 2021; Pavan & dos Santos, 2021). The abundant amount of research, development, progress, and advancement, in the area of SCD treatments provokes optimism. Nevertheless, until

there are other tested curative and therapeutic treatments, patients with SCD are limited to three main sources to either cure or reduce the negative effect of their disease: HSCT, medications, and blood transfusions.

Sickle Cell Disease Treatments that Require Donation

Two effective forms of SCD treatment (blood transfusions and HSCT), are fundamentally dependent on the extraction of SoHo such as blood, stem cells, etc., from the individual themselves (autologous), or a SoHo donor who is willing to contribute their blood products, organs, and/or tissue to treat a patient in-need (allogeneic). The reliance of many patients on a robust donor pool concomitantly demands that many eligible individuals register as donors with services that organize and orchestrate blood and tissue donation -such as the Canadian Blood Services (CBS)- and follow-through with the donation practice when, and if, they are called upon to do so.

Blood Transfusions. The statement: "Blood transfusions save lives" (Gahan et al. 2021), succinctly sums up the beneficial purpose of blood donations, as without such donations, the frequency and adequacy of the blood transfusion practice suffers. The introductory statement is especially relevant for patients suffering from SCD, as the transfusion of red blood cells is a key therapeutic intervention for individuals with the disease (Morin et al. 2020). For an allogeneic blood transfusion to be most successful, the donor's blood must be sufficiently matched to the recipient's blood group and phenotype (Gahan et al. 2021) and as various minority groups are plagued with blood diseases, such as SCD, that commonly demand transfusion (Wittock, Monforte, and Hustinx 2021), it is essential for the blood donor pool to resemble its optimum condition. This optimum condition consists of a diverse and exhaustive collective of contributors, which necessarily requires that individuals from various ethnicities participate in donating their blood products. The key factor in preserving a sustainable and satisfactory supply of blood, is a robust and consistent donor pool (Patel et al. 2019).

Where many donor registries around the globe, and particularly in Canada, encounter a problem is in relation to donor→ recipient product matching. We can observe this problem with the challenge that the CBS is currently facing. This challenge is the recruitment of donors of African descent, who have a disparate phenotype from individuals of Caucasian descent, and where individuals of Caucasian descent are the most predominant donors of blood in Canada, currently (Morin et al. 2020). This problem, as it must be mentioned, is not unique to Canada, as persons of African descent are without satisfactory representation in the blood donor population in many western countries characterized by higher income (Klinkenberg et al. 2020). Therefore, if these phenotypes corresponding to individuals of African descent are missing from the available donor pool, then those who need blood products with said phenotype will be left waiting for a proper match, which in the case of SCD, could mean that patient experiences deleterious and arduous symptoms that are able to be mitigated by transfusion.

Hematopoietic Stem Cell Transplantation. HSCT, as noted, is currently the only curative therapy available for individuals suffering from SCD. The effectiveness of this method, however, is attenuated by the fact that a mere 10-22% of patients can receive the treatment, resulting from the difficult nature of locating an eligible and willing matched donor (Pavan and dos Santos 2021); it is obvious that a treatment that relies on donated products is only as viable as the number of individuals that are willing to donate. As is the case with red blood cells, including platelets (Kreuger et al. 2020), the transplantation of HSCs is much less likely to produce adverse effects when the donor has a high degree human leukocyte antigen (HLA) match with the recipient. For example, the utilization of cord blood units (CBU) in HSCT has improved efficacy when the level of HLA match for both the CBU and the recipient is increased (Eapen et al. 2014; Dahlberg andMilano 2016, as cited in Greco-Stewart et al. 2020). The procedure of HSCT invariably

requires the stem cells to be derived from some source. As noted, that source should be as closely matched, genetically, to the recipient as possible. Taking this into account, HSCT is largely available to those patients that have a matched sibling donor, who carries an HLA identical to that of the recipient's (Leonard, Tisdale, and Abraham 2020).

An inherent issue regarding HSCT is the lack of viable sibling donors for patients with SCD. The preferred sibling donors who are HLA-matched to the recipient, are accessible to fewer than 15% of SCD patients who are prospective recipients for allogeneic blood or BM transplantation (Brodsky and DeBaun, 2020). This is a challenging area where UCB may be able to lend valuable support, given that it is a source of HSCs that may substitute BM in HSCT and is particularly beneficial when there is less than adequate compatibility between the donor and the recipient (Grano et al.2020). By consequence of the small percentage of potential HSCT recipients that have an HLA-matched sibling donor, the less preferred, albeit necessary, practice of matched unrelated donors being utilized in HSCT to provide treatment for patients with SCD is justified (Tozatto-Maio et al. 2020).

Regarding the donor population required for the alternative donor treatment to be effective, it has been noted that the task of HLA matching in genetically diverse populations (characteristic of ethnically diverse societies, such as Canada) is intrinsically more difficult (Kreuger et al. 2020). Kreuger et al. (2020:941), make the claims that an "HLA-typed donor population is mandatory to ensure sufficient support for all patients."; increased HLA-typing and donor recruitment among those ethnic groups who are missing from the donor population, could bolster the likelihood of locating a donor with satisfactory histocompatibility, based on the expansion of genetic diversity in the donor pool (Kreuger et al. 2020). Though Kreuger et al. (2020) were focusing their study on platelet donation, the preceding information derived from their work is considerably relevant to HSCT as well.

Findings of previous research have pointed to the importance of tactical recruitment in accordance with a concerted effort, through structured planning, to bolster donor commitment and retention, which increases the chance of potential donors being available to contribute to in-need patients (Greco-Stewart et al. 2020). The advancement of the services, such as the CBS's Cord Blood Bank (CBB), which collects and provides valuable cord blood units for HSCT, will widen the range of patients able to access CBU matched HSCT (Greco-Stewart et al. 2020). Moreover, a study has shown that the predicted increase in banked UCB throughout the coming decade will provide greater support to ethnic minority patients, however, this increase must be supported by the concentrated recruitment of ethnic minority cord blood donors (Allan et al. 2019).

Given the information presented, it is necessary to understand the factors, motivators, facilitators, hindrances, and barriers that influence an individual's decision to donate blood or tissue products, with emphasis on the ethnic minority communities, as doing so will allow donation services and organizations to create initiatives designed to acknowledge the needs of the targeted population in hopes of increasing donation (Murtagh and Katulamu 2021).

Motivations and barriers to donation. Religious beliefs, medical mistrust and misunderstanding regarding the medical system, an inadequate body of knowledge regarding donation, desire to aid others, fear, etc. are factors that influence one's decision to donate blood and honor such a commitment (Haw et al. 2019; Anthias et al. 2020; Gahan et al. 2021). Liao et al. (2020:585-586) found a "high degree of willingness to support the donation of blood, marrow, and other tissues for use in regenerative therapies… providing information to improve understanding of regenerative therapy increased willingness to donate.". This finding is impactful, as it shows that interventions, such as disseminating knowledge around a specific topic (e.g., regenerative therapy) to improve one's comprehension of it, may lead to the desired outcome of increasing willingness to

participate in the activity. This has implications that carry over to SoHo donation for patients with SCD, as a similar intervention may be implemented to increase understanding and subsequently increase donation. An optimistic addition by Makin et al. (2019:11) to the preceding point, is the finding that "interventions can be effective in motivating individuals from ethnic/racial minority groups to donate blood.", which demonstrates that applications, informed by research, can act to establish solutions to the issues currently present in blood and tissue donation.

Overview of The Study

This socio-cultural study drew from both inductive and deductive research traditions. A list of constructs that were deemed pertinent to blood and tissue donation were accumulated, and the indicators for these constructs were measured within the two questionnaires (the constructs and data collection methods are discussed further in the 'DATA AND METHODS' section). This predetermined list of constructs represents a deductive form of research (general→ particular).

Upon the completion of the data collection, the data were analyzed using the SPSS (statistics package for the social sciences) program from IBM. The predetermined setlist of constructs and their corresponding indicators were tested for statistical significance through both bivariate and multivariate analysis. Once the data analysis was finalized the empirical generalizations drawn from the procedure structured a causal model that illustrates the various connections between the constructs included in the research. The empirical relationships that emanated from the data represent an inductive research process (particular→ general).

DATA AND METHODS

The current study is the quantitative branch of a larger mixed-method triangulation research project that as well incorporates a qualitative branch. The quantitative portion of this project aimed at accumulating a primary data set through collecting data from various ethnic minorities in their respective communities within Edmonton, Alberta, Canada. The data collection process consisted of non-probability sampling, which included the sampling techniques: convenience sampling and snowball sampling, to locate participants of interest to take part in the research. Research assistants of various ethnic backgrounds were sent into their corresponding communities -researcher→ community matching was done to facilitate the greatest amount of trust and comfortability among the potential participants- to locate individuals to partake in the study and administer the questionnaires and video stimulus to them. In all, a total of 104 respondents were included in the study, providing the researchers with a non-representative, albeit meaningful, body of information to analyze and examine. Each participant was required to provide their consent and identify that they are at least 18 years of age to be included within the study. Respondents were also made aware of the voluntary nature of their participation, as it was made clear that they may refuse to answer any questions they may not desire to, or halt participation altogether at any point throughout the survey. Participants were assured of their confidentiality and anonymity throughout the data collection process and subsequent analysis, review, and presentation/publication of the research data.

Measures and Design

The current research was cross-sectional. A One-Group Pretest-Posttest design was employed in this study, consisting of a: pretest, treatment/stimulus, and posttest. The pretest questionnaire consisted of 37 attitudinal and behavioural questions, which measured background information, knowledge about blood and blood donation, motivations and deterrents to blood donation/experience with blood donation, and communication channels/exposure to blood donation messages. A selection of questions inquired about information relating to methods, exercises, and implementations that could be created and utilized to increase the likelihood of blood and tissue donation among community members.

Once the pretest questionnaire was completed, a stimulus was administered that was expected to act as an educational intervention with the intended purpose of increasing an individuals' likelihood of donating blood in the future. The stimulus ("MY Life Changing Treatment for Sickle Cell Anemia"- https://www.youtube.com/watch?v=eN68kz_aw4I) depicted a personal story of a SCD patient undergoing apheresis treatment to reduce the symptoms of SCD. The administration of the stimulus catered to a core principle of the research which is: that with accurate understanding of a cultural group, pedagogy can be implemented to make a meaningful difference in ethnic minority donor communities. Once the stimulus was completed the respondents were asked to fill out a posttest questionnaire.Most notably the posttest gauged how applicable said treatment was/is to the task of increasing blood donation, along with information pertaining to, and experience with, the survey itself, knowledge respondents have about genetics in relation to the donor and recipient, and the respondents' willingness to participate in a focus-group.

Constructs

The exogenous, intervening, and endogenous constructs utilized in the study are discussed below.

The data analysis included the examination of eight exogenous constructs. These included: age, gender, marital status (MarStat), respondent's racial or cultural group(s) (RacGroup), religion (Relig), level of education (Educ), current employment status (Employ), and estimated income for the past year (EstInc).

There were three intervening constructs that were investigated within the analysis: knowledge about blood and blood donation (KnowBlood), experience with blood donation (ExpBlood), and exposure to blood donation messages (CommBlood). For clarity's sake it is worth noting that an intervening construct is meant to act as an explanatory mechanism for the relationship between the exogenous and endogenous constructs, hence it is the vessel through which indirect (exogenous→ intervening→ endogenous) relationships occur (Dooley 1995:63).

There were four endogenous constructs included within the analysis. These include: likelihood of donating blood (BldDon), likelihood of donating BM (DonSCD), likelihood of supporting donating UCB (UmbSCD), and the likelihood of donating blood after the stimulus was administered (PostreatDon).

RESULTS Once the various components of the statistical analysis were completed, and the bivariate correlation coefficients and multivariate multiple regression coefficients were finalized, the data resulted in a diagram (see Figure.1) that displays the correlational and causal paths linking the designated exogenous, intervening, and endogenous constructs together- the analyses that makeup this model are discussed below.

Figure 1. Causal Model Depicting Relationships Between the Various Exogenous, Intervening, and Endogenous Constructs.

Note: Dotted Lines = Correlation/Association; Solid Single-Headed Arrow Lines= Causation.

Table 1. Sample Characteristics and Attitudes Pertaining to Blood and Tissue Donation of Ethnic Minorities in Edmonton, Alberta, Canada.

Univariate Analysis (See Table. 1)

The scale for the construct Age ranged from 18-35 where a high score reflected a greater age, a mean of 24.26 was demonstrated, therefore the sample consisted of mainly young adults; the standard deviation (SD) for this construct was 4.8. There was a majority of females within the sample: 54.8%. The majority of the respondents indicated that they were in the never married or single/separated/divorced/widowed category of the MarStat construct (75.0%), thus indicating that the majority of this sample was not in an official relationship at the time of their participation in the study. The percentage of respondents who identified as African Canadian were 26.9%, with 71.2% stating

that they were in other racial or cultural group categories- e.g., Asian, Caribbean, etc. The religious affiliation with the most diverse denominations was Christianity, a religious group that accrued a percentage of 26.0% in the sample, with the remaining proportion of the sample selecting other faiths as their religion (72.1%). The construct Education ranged on a scale from 1-8, with a higher score referring to a greater level of education and a mean of 6.16, therefore indicating that the sample was relatively well educated; the SD for this concept was 1.36. The majority of the sample, 51.0%, was employed, with 49.0% indicating that they were unemployed, keeping house, or a student. The estimated income of the sample ranged on a scale from 1-11 with a higher score being representative of greater income, the mean was 3.86, thus demonstrating that the sample was of a low-income group; the SD here was 2.88. The low-income status of the sample likely emanates from the age cohort included in the study.

Knowledge about blood and blood donation ranged on a scale from 0-10 and a higher score indicated more knowledge pertaining to blood and blood donation, the sample presented a mean of 6.13 on this composite, thus signifying a relatively well-informed sample population regarding blood and blood donation; the SD was 1.80. ExpBlood ranged on a scale of 0-2 with a higher score indicating more experience with blood donation, a mean of 0.54 was found in this composite, demonstrating that this sample had little experience with blood donation; the SD was 0.56. The sample identified that they had a high level of exposure to blood donation messages, the scale for CommBlood ranged from 0-2 and had a mean of 1.42; the SD was 0.64.

The respondent's likelihood of donating blood was set on a scale ranging from 1-6, the average on this composite was 2.33, thus reflecting a lower than average likelihood that the respondents in this sample will donate blood; the SD for this construct was 1.08. The likelihood of donating BM, surprisingly, was higher than that of blood donation, with a scale ranging from 1-5 and a mean of 3.42, it was shown that there was a high likelihood the respondents in the sample will donate BM; the SD was 1.25. The likelihood of supporting donating UCB was the highest in comparison to the preceding two endogenous constructs, with a mean of 3.77 on a scale stretching from 1-5 this sample demonstrated a high likelihood of supporting donating UCB; the SD was 1.17. The effectiveness of the stimulus was shown to be moderate-high, as the sample exhibited a mean of 1.44 on the scale of 0-2 for this composite, thus revealing the stimulus to be sufficiently successful while suggesting room for further improvement; the SD was 0.68.

Note: *P < .10, **P < .05, ***P < .01, ****P < .001 (two-tailed).

[a] Standardized Multiple Regression Coefficients

[b] Pearson's correlation coefficients

Bivariate Analysis (See Table. 2)

The following sub-section consists of the bivariate analysis[1], as shown through Pearson's ("r") correlation coefficients that demonstrated significance (view Table 2.). The concepts age, gender, marstat, and education were dropped from the causal model, as these constructs did not yield any significant causal, nor correlational, connections to any of the intervening constructs available within the analysis.

Exogenous→ Intervening. Religion was positively correlated with the intervening construct CommBlood ("r" = .232). This positive correlation suggests that those respondents who identified as belonging to the Christian faith, were exposed to greater amounts of blood donation messages. The construct RacGroup was positively related ("r" = .183) to the intervening construct CommBlood and was inversely associated with ExpBlood ("r" = -.221). The positive relationship suggests that African Canadian respondents had greater exposure to blood donation messages, whereas the inverse association suggests that African Canadians had less experience with blood donation. The concept Employ was

inversely associated ("r" = -.201) with the intervening construct KnowBlood, which suggests that respondents who were currently employed had less knowledge about blood and blood donation. The construct EstInc had a positive relationship with ExpBlood ("r" =.227). This correlation suggests that respondents who had a higher income, also had more experience with blood donation.

Intervening→ Endogenous. The intervening construct KnowBlood had a positive, moderately strong, correlation with the endogenous constructs UmbSCD ("r" = .375) and DonSCD ("r" = .349). These correlations suggest that those respondents who had greater knowledge about blood and blood donation, were more likely to donate UCB and BM to be used in curative treatments for SCD.

The concept ExpBlood had a positive relationship ("r" = .174) with DonSCD, and a strong inverse association ("r" = -.608) with the endogenous construct BldDon. The former correlation suggests that respondents who had more experience with blood donation were more likely to donate BM to cure SCD, whereas the latter correlation suggests that those respondents who had more experience with blood donation were less likely to donate blood. These correlations are curious, as one would assume that individuals who have greater experience with blood donation would be more willing to donate blood again and less likely to donate BM, as it is the more invasive procedure. This somewhat puzzling finding may be explained by the notion of altruistic fulfilment. In other words, an individual who has had experience with donating blood may feel like their debt to society, in that particular area, is satisfied and that they are not obliged to commit the same act of blood donation in the future, whereas if they have not yet donated BM, they may feel willing to contribute the product because they have not done so already. Future research should test this explanation to verify its validity.

The final intervening construct CommBlood had a positive correlation with three of the four endogenous constructs: UmbSCD ("r" = .415), DonSCD ("r" = .338), and PostreatDon ("r" = .271). The three positive correlations suggest that respondents who were exposed to greater amounts of blood donation messages, were more likely to donateand/or support donating BM and UCB to be utilized in curative treatments for SCD and were more likely to indicate a higher likelihood of donating blood after the stimulus was administered.

Multivariate Analysis (See Table. 2)

The following sub-section concerns itself with the analysis and interpretation of the standardized beta coefficients (β) (view Table 2.), as gleaned from the multiple regression analysis[2], which tests the relationship between two interval/ratio variables while all other variables in the model are being controlled for. This section is of key importance to this study, as it caters to causal relationships among the various constructs and the variables therein. The information presented here is the basis for the construction of the causal model and allows for informed decisions to be made regarding the formulation of the determinants of blood and tissue donation within the Non-White population.

Intervening→ Endogenous (Direct Relationships). The intervening construct KnowBlood had a beta coefficient (β) of .419 in relation to the endogenous construct UmbSCD, which means that when KnowBlood increases by 1 SD unit, UmbSCD increases by .419 SD units when all other variables are being controlled for. This statistic suggests that individuals who were more knowledgeable about blood and blood donation were more likely to support donating UCB to cure SCD. The construct KnowBlood had a β of .332 in relation to the endogenous construct DonSCD. When KnowBlood increases by 1 SD unit, DonSCD increases by .332 SD units when all other variables are being controlled. This suggests that individuals who had more knowledge about blood and blood donation were more likely to donate BM to cure SCD.

The intervening construct CommBlood had a β of .283 in relation to the endogenous construct UmbSCD,

which means that when CommBlood increases by 1 SD unit, UmbSCD increases by .283 SD units when all other variables are being controlled for. This causal connection suggests that when individuals were exposed to blood donation messages, they were more likely to support donating UCB to cure SCD.

Exogenous→ Intervening→ Endogenous (Indirect Relationships). The exogenous construct Religion influencedBldDon through the intervening construct ExpBlood. As Religion increases by 1 SD unit, ExpBlood increases by .257 SD units, while controlling for all other variables in the model (β= .257). ExpBlood then had a strong inverse correlation with BldDon ("r" = -.608). This finding suggests that respondents who were Christian had more experience with blood donation and were less likely to donate blood. Religion influenced DonSCD through the intervening construct ExpBlood. Religion was causally connected to ExpBlood (β= .257); ExpBlood had a weak positive correlation with DonSCD ("r" = .174). This finding suggests that respondents who were Christian had more experience with blood donation and were more likely to donate BM to be used as a treatment for SCD. The construct Religion influenced UmbSCD through CommBlood. Religion had a positive correlation with CommBlood ("r" = .232), CommBlood in turn had a causal connection with UmbSCD reflecting a β of .283. This finding suggests that respondents who were Christian, had been exposed to more blood donation messages and were more likely to support donating UCB to be used as a cure for SCD.

RacGroup influenced UmbSCD through the intervening construct CommBlood. RacGroup had a positive correlational link to CommBlood ("r" = .183), CommBlood then had a causal connection with UmbSCD (β = .283). This finding indicates that African Canadians had been exposed to greater amounts of blood donation messages and were thus more likely to support donating UCB to be used as a treatment for SCD.

Employ influenced DonSCD and UmbSCD through the intervening construct KnowBlood. Employ had an inverse correlational relationship with KnowBlood ("r" = -.201), KnowBlood in turn had a β of .332 in relation to DonSCD and a β of .419 in connection to UmbSCD. These relationships suggest that respondents who were unemployed, keeping house, or a student had more knowledge about blood and blood donation and were therefore more likely to donate and/or support donating BM and UCB to treat SCD.

EstInc influenced BldDon through ExpBlood. EstInc was causally connected to ExpBlood (β = .540), as EstInc increases by 1 SD ExpBlood increases by .540 SD units, while controlling for all other variables in the model. ExpBlood had a strong inverse association with BldDon ("r" = -.608). This finding suggests that respondents who had a higher income and had more experience with blood donation were less likely to donate blood. EstInc influenced DonSCD through ExpBlood. EstInc had a causal connection with ExpBlood (β= .540). ExpBlood then had a weak positive correlation with DonSCD ("r" = .174). This finding suggests that respondents who had a higher income and had more experience with blood donation were more likely to donate BM to be used as a treatment for SCD.

DISCUSSION

The aim of the current study was to identify determinants that influence the decision by the Non-White population to either donate or not donate blood and/or tissue products. The empirical data pertaining to these determinants presented in the research complements the objective of this study, which seeks to produce knowledge that will inform the proper facilitation of a robust 'blood donation culture' that may lead to greater, and more frequent, donation among the researched population.

From the causal connections found among the intervening constructs: KnowBlood and CommBlood, it can be seen that a base of knowledge and exposure to information pertaining to blood donation increases

the likelihood that an individual will support donating UCB and donate BM. This finding is exceedingly poignant, as the products yielded from UCB and BM are primary components in HSCT, which as mentioned previously is the only current curative therapy for SCD (Park and Bao 2021). The implications for this finding are that if the degree of knowledge individuals have surrounding blood donation and tissue donation improves, along with an increase in contact with blood donation messages, the number of individuals registered to donate UCB and BM may be increased, thus providing a greater pool of diverse and eligible donors that in-need patients may receive life-saving SoHo from.

The literature review pointed to medical misunderstandings and mistrust as being a pertinent factor that influenced donation in ethnic minority communities (Spratling and Lawrence 2019; Anthias et al. 2020; Gahan et al. 2021). The disadvantageous effects of this barrier to blood and tissue donation, may be ameliorated through the enhancement of education and knowledge pertaining to the purposes, procedures, and uses of donated blood and tissues. The rationale for the preceding statement has been demonstrated within this study. Greater amounts of blood and blood donation knowledge bolstered the likelihood that an individual would be willing to donate and/or support donating BM or UCB for medical use; such knowledge did not contribute, however, to a greater likelihood of blood donation (this may be a result of failures in operationalization, as if the concept was measured by more and/or varied indicators, the analysis may have reflected a different conclusion). Gahan et al. (2021:13) were able to demonstrate within their study that "participants believed that greater knowledge of blood donation would counter the fear and mistrust among ethnic minority communities and facilitate blood donations.". In addition, Spratling and Lawrence (2019:224) make the claim that "medical mistrust and misunderstanding presents a significant, longstanding barrier for minority blood donations; however, strategies that reduce this barrier and increase trust and knowledge can increase donations.". The preceding two studies' highlight the notion that knowledge is seen to be a primary factor in increasing donation, which was found to be evident within this study (although, more centred around tissue and UCB donation as opposed to blood donation in this specific sample). The information provided in this study supports the notion that greater collective knowledge in ethnic minority communities increases the opportunity to cultivate higher rates of donation and greater support for donation, thus bolstering opportunities for adequate healthcare for the patient community.

The finding pertaining to Employ, KnowBlood, and the likelihood of donating and/or supporting to donate BM and UCB highlights a need for more blood and blood donation education in the workplace. Organizations working in the health or social sectors that are involved in blood donation, could embark on interventions and initiatives that target various workplaces to put on educational lectures, seminars, blood drives, or events to increase the knowledge of blood and blood donation those employed in these workplaces have.

Respondents of African descent were shown to have less experience with blood donation (through a correlation). This finding agrees with results uncovered in previous studies (Makin et al. 2019). This study has confirmed that the problematized nature of the blood donation practice regarding individuals of African descent is present in Edmonton, Alberta. Furthermore, it was identified that African Canadians were exposed to blood donation messages and that they were not likely to donate blood (even after viewing the stimulus); although they were likely to support the donation of UCB. This stands as an area for improvement where organizations working to foster a 'blood donation culture' can act on. This finding demonstrates the fact that important communications pertaining to blood donation are needed to reach this minority community, as the current messages being viewed are not having the desired effect of eliciting a motivation for acting on blood donation within those exposed to these messages. Therefore, it may be beneficial to create

specific blood donation messages that predominantly focus on the African Canadian community in Edmonton, and in accompaniment with these messages an alternative educational stimulus (similar to the stimulus administered within this study) may be disseminated to bolster the effect of the messages.

Limitations

The foremost limitation to this research was the sampling method. As mentioned in the methodology section, a combination of convenience sampling and snowball sampling was used to collect data from individuals in ethnic minority communities. These methods, however, fall under the branch of non-probability sampling which has an endemic pitfall of being unrepresentative of the population. Because of this limitation, the findings are not able to be generalized to the population level. Notwithstanding this primary limitation, the findings emanating from this research provide meaningful in-depth information that originated from ethnic minorities living within the Edmonton, Alberta zone. Such data is helpful in informing blood and tissue collection and advocacy agencies, and acts as a base for further research to build off. Understanding the unique and idiosyncratic determinants of donation in our own municipality, in comparison to the universal determinants from around the nation and globe, will aid those working tirelessly for a diversified donor pool in their herculean efforts.

An additional limitation that is found within the survey is the discrepancy between the pretest questionnaire and the posttest questionnaire. Ideally, the two would ask fundamentally the same questions measuring the same variables, as doing so allows the researcher to test the validity of the treatment or stimulus being provided to alter the attitude, behaviour, or actions of the sample as indicated by changes in the constructs and their corresponding variables that are measured within the pretest and posttest. If the questions within the posttest measure differentiated variables than what is present within the pretest (as is the case within this study), then the empirical effect of the stimulus is not confidently discernable. Moving forward, studies incorporating similar methods would do well to construct their pretest and posttest in a manner that renders the effect to be observable at a higher degree than is evident in this study.

The operationalization of the endogenous construct BldDon (likelihood of donating blood) is another limitation. The concept was measured by two indicators (LikDon and App), the former indicator demonstrated a high percentage of missing cases (% 66.4), which adversely affects the validity of this indicator and therefore the findings pertaining to the concept it measures. The large number of missing cases for the 'LikDon' indicator is most probably caused by the fact that the questionnaire item containing the indicator was a contingency question; most respondents selected an answer to the original question this item was contingent upon that directed them to skip the set of items that contain the 'LikDon' measure. BldDon may have also benefited from a greater amount of more accurate indicators employed to operationalize it. An example of this could be "if you were asked today, would you consider donating blood?". Future research investigating blood donation that includes this construct should incorporate improved operationalization from what was performed in the current study.

Suggestions for Future Research

Researchers studying the determinants of blood and tissue donation in the future would do well to employ sampling techniques that utilize probability methods with random selection, in addition to a larger sample size. Both would enhance the representativeness of the study and be more conducive to population inference and generalizability of the findings. Such methods could include, but are not limited to, stratification, systematic sampling, or multistage cluster sampling combined with probability proportionate to size (Babbie et al. 2021). Many qualitative studies have been completed in relation to blood/tissue donation, therefore future research

should focus on quantitative research, incorporating causality testing, to structure an empirical basis of knowledge regarding blood and tissue donation that builds on the information presented in this study.

Subsequent research may include the testing of interpersonal relationships and how they affect the attitudes and behaviour of prospective donors. In specific, causality testing focusing on whether practicing donors have a strong influence on non-donors' willingness to donate, would be a worthwhile endeavour to undertake. If such practicing donors do accrue an influential role in this area, then donation enhancement interventions and initiatives could concentrate their efforts around mobilizing such individuals to recruit their non-donor friends to participate in donation, thus spreading awareness about donation and expanding the available donor pool.

Future research that studies the effects of educational interventions with the objective of increasing blood and tissue donation among ethnic minorities should be undertaken. The development of an educational stimulus that incorporates content displaying the blood donation and tissue donation process for first time donors may be effective in increasing the likelihood of donation in ethnic minorities, as this content would give a realistic depiction of the processes and procedures involved in donation and act to resolve misunderstanding and fear that non-donors may have. An educational intervention including this material should be tested.

CONCLUSION The findings discovered in this research reflect a need for educational tools pertaining to blood and tissue donation, and greater dissemination of well-crafted and targeted blood and tissue donation messages, that relate to the ethnic minority prospective donor population- in specific the African Canadian community. Messages that discuss the notion of a 'blood donation culture' and relay relatable and relevant anecdotal stories of individuals dealing with diseases and disorders that require support from the donor population, such as those suffering from SCD, that specifically concentrate on how ethnic minorities may provide irreplaceable aid to these individuals with disease, along with educational stimuli that consists of similar content, should be researched, created, and then disseminated to these minorities in hopes of augmenting the behavioural effect such exposure to blood donation messages may have. Exposure to such messages were shown to improve the likelihood and support of BM and UCB donations within this study (although, only through a correlation for BM), thus reinforcing the legitimacy of the recommendation for expertly designed blood donation messages to be easily and frequently accessible to those whose presence is most required within the donor population.

The essential and most applicable finding present in this study showed that through well-informed and accurate knowledge of blood and blood donation, individuals were more supportive and/or likely to participate in UCB and BM donation. Illustrating the fact that implementations, consisting of a concerted effort to improve the knowledge individuals have regarding blood and blood donation, have substantial potential to increase the amount of registered and available regular donors, and therefore, significantly contributes to the creation of an efficient and effective 'blood donation culture' that supports the health of the sickle cell disease population and others alike.

NOTE

1. The bivariate analysis of the constructs: employment and likelihood of donating blood, suffered from multicollinearity. Therefore the bivariate analysis between these two constructs and their corresponding variables was excluded.

2. CommBlood was removed from the multiple regression analysis where BldDon was placed as the dependent variable and the remainder of the exogenous and intervening variables were placed as the predictors. The issue of multicollinearity was

occurring within this model when CommBlood was included, hence why it was disqualified.

Table 1. Sample Characteristics and Attitudes Pertaining to Blood and Tissue Donation of Ethnic Minorities in Edmonton, Alberta, Canada.

CONCEPT	*MEAN or %*	*STANDARD DEVIATION*
Exogenous		
Age	Mean = 24.26 Range= 18-35	4.8
Gender	0. Female = 54.8 1. Male = 45.2	
Marital Status	0. Married/common-law = 24.0 1. Never married or single/separated/divorced/ widowed = 75.0	
Racial or Cultural Group(s)	0. Other = 71.2 1. African = 26.9	
Religion	0. Other = 72.1 1. Christian = 26.0	
Education	Mean = 6.16 Range = 1-8	1.36
Employ	0. Unemployed, keeping house/student= 49.0 1. Employed = 51.0	
Estimated Income	Mean = 3.86 Range = 1-11	2.88
Intervening		
Knowledge of Blood And Blood Donation	Mean = 6.13 Range = 0-10 (Higher score = more knowledge about blood)	1.80
Experience with Blood Donation	Mean = 0.54 Range = 0-2 (Higher score = more experience with blood)	0.56
Exposure to Blood Donation Messages	Mean = 1.42 Range = 0-2 (Higher score = more exposure to blood donation messages)	0.64
Endogenous		
Likelihood of Donating Blood	Mean = 2.33 Range = 1-6 (Higher score = more likely to donate blood)	1.08
Likelihood of Donating Bone Marrow	Mean = 3.42 Range = 1-5 (Higher score = more likely to donate bone marrow for a cure for SCD)	1.25
Likelihood of Supporting The Donation of Cord Blood	Mean = 3.77 Range = 1-5 (Higher score = more likely to donate cord blood to cure SCD)	1.17
Effectiveness of the Stimulus	Mean = 1.44 Range = 0-2 (Higher score = higher treatment effect)	0.68

Note: N= 104.

Table 2. Standardized Multiple Regression Coefficients and Pearson's "r" Correlation Coefficients.

CONCEPTS		*INTERVENING*		
EXOGENOUS		Knowledge of Blood and Blood Donation	Experience with Blood	Exposure to Blood Donation Messages
	Religion		.257[a*] .086[b]	.232[b**]
	Racial or Cultural Group(s)		-.221[b**]	.183[b*]
	Employ	-.201[b*]		
	Estimated Income		.540[a***] .227[b*]	
ENDOGENOUS	Likelihood of Supporting the Donation of After-birth Material	.419[a***] .375[b****]		.283[a**] .415[b****]
	Likelihood of Donating Bone Marrow	.332[a**] .349[b****]	.174[b*]	.338[b****]
	Likelihood of Donating Blood		-.608[b****]	
	Effect of Stimulus			.271[b**]

Note: *P < .10, **P < .05, ***P < .01, ****P < .001 (two-tailed).
[a] Standardized Multiple Regression Coefficients
[b] Pearson's correlation coefficients

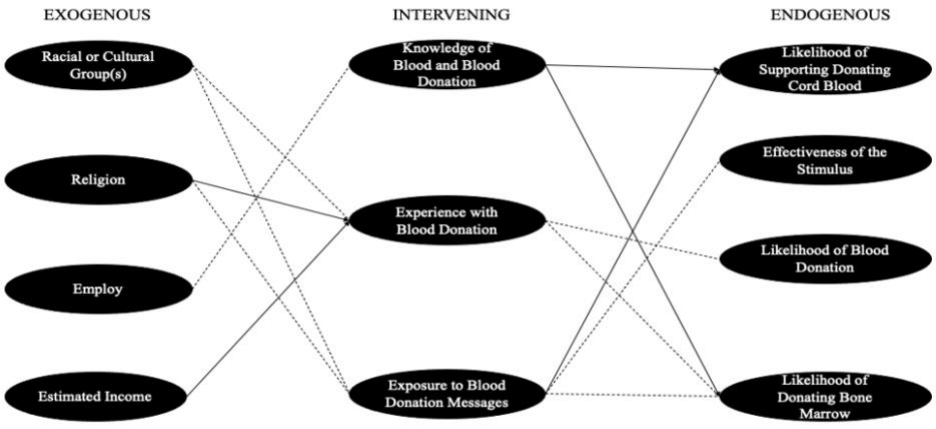

Figure 1. Causal Model Depicting Relationships Between the Various Exogenous, Intervening, and Endogenous Constructs.
Note: Dotted Lines = Correlation/Association; Solid Single-Headed Arrow Lines= Causation. Univariate Analysis (See Table. 1)

JSCDH-D-21-1118478

TRANSITIONING FROM PEDIATRIC TO ADULT CARE IN SICKLE CELL DISEASE

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Background: Advances in pediatric sickle cell care have resulted in children with sickle cell disease surviving into adulthood, increasing to 95% by the age 18. There is an abrupt rise in mortality rates between 20 to 24 years of age, usually within 1-2 years after transfer to adult care. Transition is a time when continuity of care is essential to prevent high rates of morbidity and mortality in adolescents and young adults (AYA). This descriptive study evaluated patients and caregivers' feedback of the health care transition experience after transition by feedback and post-assessment transition surveys.

Methods: We surveyed AYA 20-21 years of age at Children's National Hospital who transitioned from pediatric to adult care. Feedback and post-assessment surveys were conducted with AYA who attended the Sickle Cell Adolescent and Young Adult Transition Clinic (SCAT). Post-assessment surveys were conducted with AYA who did not attend SCAT. Data was analyzed using descriptive statistics.

Results: 59 AYA with SCD attended SCAT and 15 did not attend, from January 2018- January 2021. After transition to adult care, AYA were called for follow up;88.5% of the AYA who attended SCAT had been seen by their adult provider since leaving their pediatric provider, and 89% were satisfied with the care they were receiving. All AYAs (n=15) who did not attend SCAT had seen their adult provider and they were all satisfied with their care.

Conclusions: Most caregivers report AYA were well prepared to transition from pediatric to adult care. The preparation AYA received promoted self-efficacy to manage their own health care. Of note, for those who did not attend the SCAT clinic, they were helped to find an adult provider and their medical records were sent before the first visit. The transition process should start earlier than age of 18, so AYA can begin preparation to self-manage and have the confidence needed to transition.

JSCDH-D-21-1107418

WOMEN'S PERCEPTION ABOUT THE EXPERIENCE OF PRIAPISM IN THEIR PARTNERS

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Background: To comprehend the perception of women about the experience of priapism in their partners.

Methods: Qualitative study carried out at the Reference Center for People with Sickle Cell Disease in Feira de Santana, Bahia-Brazil. The study subjects were women whose partners have or have had priapism as a complication of sickle cell disease. The ethical norms of Resolution nº 466/2012 of the National Health Council were respected. Data were collected through semi-structured interviews. Then, they were submitted to thematic content analysis.

Results: Five women participated, whose partners have or have had priapism as a complication of the disease. The age range of the interviewees ranged between 19 and 57 years. Most are white, have low education and income and do not live in Feira de Santana. The time of relationship with their partners ranged between 4 months and 20 years and all of them have other complications of SCD in addition to priapism. From the findings, four categories and two subcategories emerged: 1) Lack of knowledge of the partners in relation to priapism and sickle cell disease; 2) Fear of complications and death of the partner; 3) Erectile dysfunction as a complication of priapism in sickle cell disease compromises the couple's sexuality; 3.1) Man's embarrassment in the face of episodes of priapism and erectile dysfunction; 3.2) Strategies used by men in situations of priapism and erectile dysfunction; 4) Resignation of women facing the difficulty of sexual practices.

Conclusions: There are several implications that priapism generates in the lives of men with sickle cell disease and their partners. It is necessary to expand the discussions about sickle cell disease and its complications, so that the companions can better understand the topic and, thus, be prepared to deal better with the situations that may arise. This requires a multidisciplinary team focused on holistic and humanized care for all family members. Nurses are essential in this regard, as they are able to raise problems and prevent injuries for both the patient and their families.

TABLE OF AUTHORS