HPJ

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Photo “Lessons of the African Black Rhinoceros” submitted by Lynette Peters.
Read more inside.

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Cover Artwork

Lessons of the African Black Rhinoceros

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Artist Statement

Clay is a vernacular. In this medium, my inclination to abstract expression answers only to the boundaries of the natural laws of science in the processes of clay-form and glaze. Injustice is often the centrepiece, layered by multiple and intended meanings for the observer to find.

The African Black Rhinoceros informs the process and production of three artforms representing our past, present and future. Through its tenacity as a species to continue to exist amidst extreme anthropogenic pressures, its transition is as symbolic as the innovative measures of its conservation.

In three hammocks, porcelain clay-forms of *equal* dimensions were suspended *unequally* from the light resulting in unique artforms. This process is shown in the image to the right.

Past, White

Ghosts of the Past

Cone 6, White Porcelain, Plainsman Polar Ice (Canada)

Present, Black

Change and Human Transition

Cone 6, Black Porcelain, SiO2 Black Ice (Spain)

Future, Bright Blue

Hope for the Uncertain

Cone 6, Blue Porcelain, SiO2 Upsala Blue (Spain)

Author Biography

Lynette A. Peters is a PhD student in Health and mother of five. Supervised by Dr. Alice Aiken, Lynette's dissertation work will include the topics of creative avocations and Canadian Military Veteran health and well-being. Personal and entrepreneurial pursuits in the ceramic arts led her to establish Cerberus Pottery, an avocational studio designated for active and retired military members and First Responders.

Lynette obtained graduate degree at the University of Windsor in Applied Human Kinetics and undergraduate degree in Biology from Queen's University in Kingston, Ontario.

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CROSSROADS INTERDISCIPLINARY HEALTH RESEARCH CONFERENCE

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Healthy Populations Institute

Welcome from the Healthy Populations Institute

On behalf of the Healthy Populations Institute (HPI) we would like to welcome you to the first Healthy Populations Journal (HPJ). We are thrilled to be supporting this worthy student-led initiative.

HPI is a multi-faculty research institute at Dalhousie University that is jointly funded by the Faculties of Health, Medicine, and Dentistry. HPI is comprised of scholars, students and community partners that aim to improve population health in Atlantic Canada and beyond by understanding and influencing the complex conditions that affect the health of communities. Our new strategic plan launched in May 2020 and focused our efforts on advancing knowledge generated from our research into effective changes in population health related policy and practice. One important way to fufill our mandate is supporting HPJ. We are delighted to be supporting student leaders and publishing student-led, peer-reviewed work that aligns with the United Nations Sustainable Development Goals and/or HPI's five current Flagship Projects.

What's even more special about this inaugural HPJ Special Edition is that it is in collaboration with the Crossroads Interdisciplintary Health Research Conference. As in previous years, Crossroads is a demonstration of the leadership and passion of Dalhousie's students, along with students from across Canada, and provides an excellent opportunity for knowledge sharing, networking and capacity building. HPI is proud to be the new host organization of the Crossroads Conference and excited to use HPJ as an opportunity to disseminate high quality student work that would usually be presented at an annual in-person Crossroads event.

We hope that HPJ presents you with an opportunity to expand your population health knowledge, challenge your thinking, and support the excellent research being conducted by student scholars.

Congratulations to the HPJ Executive Team that has worked so hard on this first release.

Sincerely,

Sara Kirk

Gillian Ritcey

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Welcome from the Co-Editors-in-Chief

We are so pleased to welcome readers to the inaugural issue of the *Healthy Populations Journal* (HPJ). The HPJ is a new student-run open-access journal out of Dalhousie University that provides a space to highlight student-led population health research. The journal was born out of a strong desire to continue to support student health research despite the COVID-19 pandemic requiring the cancellation of the 2020 and 2021 annual student-led *Crossroads Interdisciplinary Health Research Conference* hosted by Dalhousie University. While we acknowledge that COVID-19 has led to significant disruptions to research, we wanted to provide this space for students to share and publish research as well as original commentaries, visual artworks, and poetry that are related to population health and/or health equity. We hope this journal can circumvent some pandemic-related interruptions and increase graduate student involvement in academic publishing.

Part of our vision for HPJ is to feature diverse and intersectional forms of knowledge expression and approaches and we encourage the submission of artistic works. Our cover features sculpture work by PhD trainee Lynette Peters. The articles by Stone et al. and Stirling Cameron and Jefferies feature original artwork by master's student Emma Stirling Cameron. This issue also features a poem by Master's student Lindsay Dorder. While artistic works are a little non-traditional in academic publishing, we felt it was important to offer students a space use their artistic talents to enhance knowledge translation and dissemination of health research.

Articles in this issue cover timely and important topics and would be interest to a variety of readers. Joshi and Stone discuss the importance of play for children during the pandemic while Caldwell reflects on her time working the Covid-19 hotline. Tomas describes the role of leisure in shaping identity among immigrant students in Halifax, Nova Scotia. Ajadi and Rodgers assess the representation of people of African descent on community health boards in Nova Scotia. Stirling Cameron and Jefferies release a call to action on anti-black racism in the Canadian education system. Jefferies and Price offer a scholarly narrative on African Nova Scotian nursing leadership. Stone et al. discuss gender and racial inequities in relation to climate change. Nashnoush and Sheikh offer a philosophical approach to the morality of suicide. Cassidy et al. provides recommendations on improving the pediatric to adult care transition experience based on findings from young adults with complex care needs while Kelly et al. discuss the development and implementation of a Facebook-based peer-to-peer support group for caregivers of children with complex care needs in New Brunswick.

The HPJ would not be possible without support from the Healthy Populations Institute at Dalhousie University, and especially the hard work of our managing editor and co-founder, Sara Brushett. We would also like to extend our appreciation to the editorial board for their commitment to creating a journal based on our guiding principles and competencies. Further, we are grateful to our peer reviewers for offering their time, expertise, and constructive revisions. And finally, thank you to all of the authors that submitted articles and artwork to HPJ. We recommend readers consider submitting their work to HPJ for future issues.

We sincerely hope you enjoy reading this issue.

Christie Stilwell
PhD in Health Student, Dalhousie University
Co-Editor-in-Chief, HPJ

Dr. Justine Dol, PhD
PhD in Health, Dalhousie University
Co-Editor-in-Chief, HPJ

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Commentary

25 Days on the COVID-19 Hotline: Reflections on Competency Development From a Health System Impact Fellow

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Abstract

When COVID-19 began to spread across Canada in 2020, local public health units and authorities began to implement emergency response teams. The purpose of this commentary is to describe my embedded learning experience at a public health unit during the first wave of COVID-19 in Canada. Using the enriched core competencies for health services and policy research doctoral graduates developed by the Canadian Health Services and Policy Research Alliance's Report from the Working Group on Training, this article describes the development of core competencies of an embedded fellowship before and during the COVID-19 response. I describe the learning and shift in core competency development that resulted as I was deployed to the COVID-19 Hotline in Spring 2020.

25 Days on the COVID-19 Hotline: Reflections on Competency Development From a Health System Impact Fellow

From September 2019–August 2020, I participated in the Canadian Institutes of Health Research Health System Impact Fellowship program at the City of Hamilton Public Health Services (PHS). My fellowship was intended to broadly focus on the implementation and evaluation of public health projects related to physical activity and active transportation. My academic training was in kinesiology and this was my first experience outside of academia, health research, or recreation. At the beginning of March 2020, I went to a conference for a few days, and when I returned I found that most of my PHS colleagues had been deployed to COVID-19 roles. That same week, my university moved to online learning and sent everyone to work from home. On Sunday, March 15, my manager at PHS emailed me, asking me to call her immediately. I think I knew what was coming (she had never emailed me on the weekend before). She asked if I would help with the COVID-19 Hotline. After all, I was at PHS to be embedded and learn about the health system. In public health, there is no better learning opportunity than a quickly evolving pandemic. I told her I would help, thinking I would report sometime that week, but she asked if I could come to the office immediately for training. I was there until 9 p.m. The training was brief, and I was quickly live on the COVID-19 Hotline.

My first shifts were exhausting. There were very few provincial regulations in place, and it seemed like everyone was calling us for guidance. I talked to restaurant owners, barbers, and dentists who wanted advice on how to operate safely. Some of the calls were sad or challenging, but nothing was as hard as telling people—repeatedly—that they were not eligible for testing. Before testing capacity expanded, we only referred those who had symptoms and either a travel history outside of Canada or close contact with a confirmed case. The calls looking for test results were equally challenging. For a short period of time, testing capacity at labs was limited and it was taking more than a week to phone people back with test results. One of the Public Health nurses told me the stack of callbacks just kept getting bigger and bigger (thankfully these long delays have since been resolved). We had callers who needed test results in order to get back to work, and all I could do was apologize and ask them to wait a few more days. In addition to these calls, I was going home and reading everything I could about COVID-19, in order to relay quality information to callers the next day. At this point, I was six months into my fellowship and deeply embedded in my learning within the health system.

In addition to embedded learning, professional development was a core component of the Fellowship program. Using the enriched core competencies for health services and policy research doctoral graduates developed in the Canadian Health Services and Policy Research Alliance's Report from the Working Group on Training (Bornstein et al., 2018; Canadian Health Services and Policy Research Alliance, 2015), I completed a plan and self-evaluation of these competencies early in my fellowship (see Table 1). Looking back to my first self-evaluation, I identified the following top three competencies that I planned to target over the course of my fellowship:

1. Analysis and Evaluation of Health and Health-Related Policies and Programs
2. Understanding Health Systems and the Policy-Making Process
3. Analysis of Data, Evidence and Critical Thinking

These three core competencies are considered Research and Analytic Skills (see Table 1). In the first six months of my fellowship, pre-COVID-19, I was developing these skills as I learned about different aspects of PHS and carried out evaluation projects. My experience on the COVID-19 Hotline highlighted the importance of developing the Professional Skills included in the core competencies.

The first lesson I learned on the Hotline was to listen, a key component of Dialogue and Negotiation. I needed to be empathetic to callers, effectively communicate public health messaging, and resolve conflicts when callers were disappointed with the public health response. These skills will go a long way in my career, reminding me to listen more than I think I need to. The hotline team was diverse, and included staff from several PHS divisions and departments, including public health inspectors, registered dieticians, and health promotion specialists. This was truly Interdisciplinary Work as we collaborated to provide the best responses to callers. If I didn't know an answer, I could put the caller on hold and discuss the answer with my colleagues, drawing on everyone's unique skills and experience. This was also an excellent Networking opportunity to build relationships through engaged communications with colleagues from other teams at PHS. I was so impressed by my colleagues' knowledge, skills, and passion for public health. In this public health emergency, everyone was part of the response.

My public health COVID-19 experience was also a front-row seat to Change Management and Implementation. I was not leading the change, but I adapted to it every day. Each shift on the Hotline brought changes in processes and messaging to callers. Without organizational awareness, adaptive thinking, and resilience, my role would have been impossible. I observed leaders across PHS change processes quickly to adapt to new announcements from the various levels of government. Table 1 outlines the skills I identified that I expected to develop in my fellowship, and interestingly, the three skills not selected were the three that I learned the most about (Interdisciplinary Work, Dialogue and Negotiation, and Networking).

COVID-19 absolutely changed my fellowship experience as I developed unanticipated professional skills that will be essential to my career development. I am thankful that I witnessed and experienced how PHS approached the COVID-19 response professionally, swiftly, and effectively. After 25 days on the COVID-19 Hotline, I was deployed to a data management role. I know some colleagues are still deployed to the Hotline, helping Hamiltonians every day as they navigate this new normal. COVID-19 is proving to be a marathon public health response, and I am so appreciative of and impressed by those workers still in the race.

[Please see Table 1 on the following page.]

Author Note

Dr. Hilary Caldwell was supported by a Health System Impact Fellowship, jointly funded by the Canadian Institutes of Health Research and City of Hamilton Public Health Services. I am grateful to my academic and health system mentors who supported this work, particularly Dr. Brian Timmons, Dr. Bart Harvey, Kevin McDonald, Ann Stanziani, and Claire Lechner.

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Table 1

Expected and Developed Enriched Core Competencies for Health Services and Policy Research During an Embedded Public Health Learning Experience

Skills	Attributes/ competencies	Description	Expected Core Competencies	Developed Core Competencies
Research and Analytic Skills	Analysis and Evaluation of Health and Health-Related Policies and Programs	The ability to effectively carry out formative and summative evaluation with strong links to organizational improvement and planning. Includes technical skills, contextual awareness, communication skills, analysis skills, and research skills	X	
	Analysis of Data, Evidence and Critical Thinking	The ability to collect, analyze, and use a wide range of data, and to reflect critically on and incorporate theory and research evidence iteratively to clarify problems, frame options, and identify implementation considerations in both academic and non-academic settings. Includes big data, administrative data, and economic data	X	
	Understanding Health Systems and the Policy-Making Process	Excellent knowledge of the Canadian and international health policy system from both academic and real-world perspectives	X	
	Knowledge Translation, Communication, and Brokerage	The ability to use multiple methods of communication and to communicate appropriately with different audiences	X	X
Professional Skills	Leadership, Mentorship, and Collaboration	The ability to lead, organize, and support teams from various backgrounds to work together to achieve a specific outcome	X	
	Project Management	The ability to coordinate and organize all stages through to KTE of a project in an academic or non-academic environment	X	
	Interdisciplinary Work	The ability to use effectively, and combine when appropriate, methods and insight from multiple academic disciplines (e.g., humanities, social sciences, management, epidemiology, medicine, etc.)		X
	Networking	The ability to develop and maintain productive relationships inside and outside of academia across the health system		X
	Dialogue and Negotiation	The ability to work toward win-win outcomes and value-added results, including understanding other perspectives and how to respond		X
	Change Management and Implementation	The ability to plan, manage, and implement change, including the following: to communicate a clear vision for change; to lead people and organizations through change; to manage and implement successful transitions; and to evaluate and report on change	X	X

Note. Adapted from *Report from the Working Group on Training* by Canadian Health Services and Policy Research Alliance (2015), p. 13.

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Commentary

Anti-Black Racism in Canadian Education: A Call to Action to Support the Next Generation

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This artwork is dedicated to our daughters, and the next generation of Black learners. For them, we must work diligently to close the achievement gap and improve access to education for Black students and dismantle the legacy of anti-Blackness in public education and the academy, because Black Lives Matter. Artwork by ESC.

The systematic brutalization of Black people has persisted since colonization, but police murder, global anti-racism protests, and a pandemic that has disproportionately impacted racialized communities have brought anti-Black racism to the attention of the global community. The insidious nature of White supremacy has given birth to anti-Black racism, which has shaped institutions of public and post-secondary education across Canada. Institutional racism is harmful and continues to negatively impact the trajectories of Black lives. For example, Black children are more likely to be enrolled in under-resourced schools, receive harsher punishments, and be streamed into non-academic programming regardless of academic potential and capability. Moreover, Black students are less likely to attend university, despite wishing to, and Black educators remain under-represented and undervalued, despite their immeasurable contributions to academia and the Black community. These examples represent a concerted effort to guard White spaces and keep Black people from accessing equal opportunity through basic access to education. This paper is a call to action for all educators, allies, and institutions to begin to make reparations and end the racial hierarchy and systematic anti-Black oppression across Canada because Black Lives Matter.

Many Black students in Canadian public schools receive an education that is separate and unequal from that of their peers (Teklu, 2012), steeped in a legacy of segregation and anti-Blackness—a disparity that has gone largely unchanged for decades (Black Learners Advisory Committee, 1994). With majority White teachers and Eurocentric curricula—largely ignoring Canada's history of enslavement and segregation (Black Learners Advisory Committee, 1994)—students report feeling unwelcome and unseen. Only 54% of Black students report feeling supported by their teachers (Rankin et al., 2013). Often seen as a threat to the education of their White peers (Maynard, 2017), Black youth—especially Black boys—face more frequent, severe punishments. Black students accounted for half of all expulsions in Toronto in 2016 (Chadha et al., 2020). Black students are more likely to be pushed into non-academic streams and away from STEM subjects, a phenomenon referred to as second-generation segregation (Maynard, 2017; Mickelson, 2007); From 2006–2011, 53% of Black students in the Toronto area were in an academic stream, compared to 81% of White students (Chadha et al., 2020). Black high school students, regardless of their grades, are often dissuaded from university education and pushed toward vocational training (Gaynair, 2017; Maynard, 2017). Consistently undervaluing and criminalizing Black students contributes to psychological stress and harm, impacting child development and disincentivizing students from attending classes and continuing their education (Black Learners Advisory Committee, 1994). Just 69% of Black students graduated high school in Toronto between 2006 and 2011, compared to 84% of White students. While almost 60% of non-Black students applied to post-secondary school, only 42% of Black youth applied (Chadha et al., 2020).

Universities across Canada remain privileged, predominantly White spaces. Despite 94% of Black youth in Canada reporting that they would like to obtain a bachelor's degree (or higher), only 60% reported thinking it was attainable (Statistics Canada, 2020). Students whose dreams of higher education were not thwarted by unsupportive, punitive, public education still face barriers to entering and remaining in undergraduate programs. The exponentially rising cost of tuition across Canada and the continued reliance on merit-based admission disadvantages Black students, who are two times as likely to live in a low-income household (Statistics Canada, 2020). At Dalhousie University in Nova Scotia, only 2% of the student body is Black, compared to a 5% population rate in the province (Bombay & Hewitt, 2015). Student experiences depict a normalization of anti-Blackness on campuses—microaggressions, racial slurs, privatized policing, violent threats, and even outspoken disdain from professors—most of which is often dismissed by those in positions of power (Bell et al., 2020). Buildings and statues on campus pay homage to slave owners and segregationists (e.g., George Ramsay at Dalhousie University, Halifax; James McGill at McGill University, Montreal); it is a stark reminder of the origins of the academy. Students who have not been pushed out and continue into graduate studies describe encountering covert racism from spaces that preach liberalism: struggling to find supervisors, being discouraged from pursuing critical research, and being held to higher academic standards than White students (Bell et al., 2020).

Black faculty members are under-represented across Canadian universities. For example, Black faculty at McGill University constitute only 0.8% of their faculty, despite accounting for 4% of Quebec's population (Hinkson & Shingler, 2020). Black professors earn lower salaries than their White colleagues and are less likely to be promoted and awarded tenure, despite a high level of academic achievement (Henry et al., 2017). A Black faculty member in Henry and Tator's (2012) study said, "I was told by a senior racialized colleague that you have to publish 20 times better than your White colleagues to get tenure" (p. 89). Often referred to as Black tax (Gewin, 2020), the few racialized faculty that often exist within a department are repeatedly asked to serve on diversity committees and admission boards, all in addition to their regular demands of teaching and research. This is in addition to supervising higher rates of students (mostly of colour) and partaking in community activism and policy work to better the Black community—all of which typically goes unpaid and unrecognized, and is not considered in tenure applications. Black faculty are, therefore, undercompensated for the amount of scholarship and leadership they actually engage in and have less time to devote to research and publication, which remains a critical marker of academic success and productivity (Gewin, 2020).

We put forward a short list of calls to action for individuals and public and private institutions to enact to better address gaps in educational access, attainment, and achievement for Black learners and educators:

- establish Afrocentric curricula for public and post-secondary institutions (e.g., African Canadian Studies course in Nova Scotia high schools [Province of Nova Scotia, 2015]; Africentric Alternative School [James, 2011]; Black and African Diaspora Studies [McNutt, 2020]);
- implement funding programs to train and employ Black teachers (Black Learners Advisory Committee, 1994);
- survey programs/faculties to determine what has been successful in increasing the representation of Black students and implement strategies to recruit and retain Black students and faculty (e.g., University of Toronto Faculty of Medicine Black Student Application Program recruited 24 Black medical students in 2020, the most in Canadian history; Collie, 2020);
- work to tackle personal biases, while also working to dismantle systemic racism in meaningful, non-performative ways (Bell et al., 2020);
- recognize and compensate Black staff for invisible labour (e.g., panels, committees) and community contributions (Gewin, 2020);
- increase designated undergraduate and graduate scholarships or tuition waivers for Black students (see Mount Saint Vincent University and Memorial University tuition waiver for foster children; Bombay & Hewitt, 2015; McPhee, 2020); and
- advocate for the improvement of the social and economic conditions that systematically and disproportionately impact Black families, in meaningful, non-performative ways. This includes the following:
    - coverage for quality daycare/child care
    - financial investment in historically/predominantly Black communities and schools
    - basic income and living wages ($2,100 per month in Canada; WageIndicator Foundation, 2020)
    - free tuition and student debt relief

Despite a lasting legacy of racial inequities and hierarchies, Black families, educators, and activists have resisted centuries of White oppression and segregation. In 2017, nearly 70% of Black adults in Canada had a post-secondary diploma of some kind and the majority of the Black population reported that their education and employment opportunities were better than those of their parents (Statistics Canada, 2020). These improvements in income and quality of life are owed to the generations of Black leaders and activists who fought persistently for equity and inclusion (most of whom have pushed for the implementation and awareness of the listed calls to action). It is imperative for the next generation of learners that swift, wide-sweeping, evidence-based action be taken to improve the accessibility of quality education for Black learners (Black Learners Advisory Committee, 1994; Chadha et al., 2020; Maynard, 2017).

Acknowledgements

The authors would like to acknowledge that Black learners are not the only population who has experienced systematic oppression. Indigenous learners across Turtle Island have had their own experiences of colonization, assimilation, and discrimination, all of which impacts their access to quality education. Many of these calls to action extend to Indigenous students and faculty.

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Commentary

Playing During a Pandemic: Why Children Need Outdoor Play More Than Ever

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Every child has the right to play (International Play Association, 2012), especially outdoors. The benefits of outdoor play are long-lasting and are endorsed through a position statement targeting stakeholders who influence children's health and development (Tremblay et al., 2015). This statement was developed to support children's opportunities for self-directed play outdoors, and aimed at key early years stakeholders, including parents, educators and caregivers, health and injury prevention professionals, school and child-care administrators, schools and municipalities, media, and government and policy-makers. It describes how spending time outdoors is fundamental to children's physical, mental, and emotional development, and offers a space for them to explore, experiment, and understand their surroundings (Tremblay et al., 2015).

When children participate in active outdoor play, they can move freely, take risks, and challenge themselves (e.g., climbing, exploring new environments); learn their own limits; become more confident, independent, and resilient; learn how to problem-solve; develop different movement behaviours; and foster healthy relationships (Tremblay et al., 2015). When children are outdoors, particularly in nature, they are happier, experience less anxiety, and have more energy (Brussoni et al., 2015). When children do not have the opportunity to play outside, they are at a greater risk of developing mental illness (e.g., anxiety, depression) and chronic diseases later in life (Gray et al., 2015).

Unfortunately, children's opportunities to play freely outdoors have declined significantly over time, resulting in a rise in non-communicable chronic diseases (Tremblay et al., 2015). There has been growing advocacy around children's outdoor play; in Canada, this has been spearheaded by the Lawson Foundation's Outdoor Play Strategy (Alden, 2016) and by Outdoor Play Canada, a growing network of advocates, practitioners, researchers, and organizations focused on supporting access to play and nature in the outdoors (de Lannoy et al., n.d).

The Impact of COVID-19 on Outdoor Play

The sudden emergence of COVID-19 and the public health protocols put in place to control the virus have both had a direct effect on outdoor play opportunities for children. Although emerging evidence has shown the virus to infect children less critically than adults, restrictions have been established to prevent the spread to the greater population (Public Health Ontario, 2020). These restrictions have resulted in the closures of schools, playgrounds, recreation centres, and parks, and have set limits on social gatherings (Government of Canada, 2020).

As a result of these restrictions, Canadian children are spending more time indoors, sedentary, and on screens (Moore et al., 2020). Lockdowns in other parts of the world have revealed impacts on children's mental health. Parents in Italy and Spain reported a perceived change in their child's emotional well-being, observing symptoms such as difficulties concentrating, restlessness, and feelings of loneliness (Orgilés et al., 2020). The unexpected change in regular routine and sudden isolation from peers, educators, family members, and other social supports may have left children feeling a loss of control (Merenda & Martyn, 2020). These feelings are likely exacerbated by restrictions on how, where, and with whom, children can play.

Outdoor play serves as a unique mechanism for children to make sense of their surroundings while giving them the independence and sense of control that is particularly important during this time (Dodd & Gill, 2020). Through play, children are able to process difficult situations, express their emotions, and develop their social identities, all of which can help alleviate the stress and anxiety they may be feeling as a result of public health protocols to control the virus (Dodd & Gill, 2020). During these challenging times, children need play more than ever to help them cope with uncertainty and alleviate stress. Several Canadian organizations have released statements on the importance of outdoor play during the pandemic, and strongly recommend that early years settings prioritize and provide regular opportunities for quality outdoor play experiences (de Lannoy et al., n.d; Mayer, 2020; IPA Canada, n.d). Our Physical Literacy in the Early Years (PLEY) research team is supporting this call to action.

The Evolution of the PLEY Project and PLEY School

The PLEY research team was established at Dalhousie University, and includes an interdisciplinary and multi-institution partnership of researchers focused on improving outdoor play experiences of children living in Nova Scotia (NS). As part of the Lawson Foundation's Outdoor Play Strategy, our PLEY project integrated loose parts into the outdoor spaces of 19 child care centres across NS and examined the impact on children's physical literacy and other aspects of health and development (Houser et al., 2016). Loose parts are natural and/or synthetic materials that can be moved, manipulated, carried, or combined in various ways (e.g. wooden planks, buckets, tubes) (Houser et al., 2016). The open-endedness of loose parts play affords children many physical, cognitive, and social-emotional benefits (Houser et al., 2016).

With funding from Research Nova Scotia (2019–2022), our team is integrating loose parts into the outdoor spaces of before- and after-school programs across NS. The first step will be to investigate the impact of the pandemic on the family unit, specifically the physical and mental health of children living in NS, and the role of outdoor play in supporting family health and well-being during this time. Our multi-methods approach with parents (surveys and interviews) and children (individual interviews and write, draw, show, and tell methodology) (Noonan et al., 2016), will address important gaps in the literature, most notably allowing children to share their lived experiences of the pandemic in terms of outdoor play opportunities and the impact on their physical and mental health.

We believe these findings will help solidify the importance of ensuring NS children have access to quality outdoor play experiences where they live, learn, and play, both during and after COVID-19. We will also work with educators to understand the benefits and challenges of delivering outdoor play, particularly during the pandemic, and provide training that fits the context of their play environment. Likewise, we will work with parents and community partners to inform the content and delivery of our training. Through this research, we hope that educators and other early years stakeholders, locally and nationally, will have the tools and resources they need to provide quality outdoor play experiences for children during these challenging times.

Outdoor play is critical in helping children adapt to the uncertainty presented by COVID-19, while helping them keep physically and mentally well. While restrictions are in place to control the spread of the virus, more work needs to be done to support educators and stakeholders on how to provide quality outdoor play experiences for children during these uncertain times. Our PLEY School project will be a critical step in understanding how to support quality outdoor play during COVID-19, and ensuring that places and spaces in which children learn and play across NS provide an environment where children's health and development are optimized.

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HPJ HEALTHY POPULATIONS JOURNAL

Commentary

Tackling Gender and Racial Inequities: Climate Solutions for All

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Image depicts three young women known for their environmental and human rights activism. From left to right, Greta Thunberg, Autumn Peltier, and Mari Copeny (Little Miss Flint) exemplify the knowledge, power, and experience of organized justice movements needed to address the climate crisis. Artwork by ESC.

Climate change has been labeled the "biggest global health threat in the 21st century" (Costello et al., 2009, p. 36). This statement, now a decade old and commonly repeated in climate and health discourse, is only partly true because it neglects to consider the social context of climate change. Hurricanes are increasingly more frequent and less predictable, droughts and fires are more widespread, sea ice continues to melt, and sea levels rise. Populations who have been marginalized, including women, Indigenous peoples, people of colour, and people with low income or in low-income countries, experience the brunt of the climate crisis (Hayes & Poland, 2018). There is significant overlap between racial and gender inequities and the climate crisis, and tackling oppressive systems may be key to sustaining life on earth. We will need the strongest climate team, the most inclusive and powerful solutions, and the knowledge to dismantle the similar systems and structures that simultaneously sustain oppression and climate change.

The Strongest Team

Dr. Ayana Elizabeth Johnson, marine biologist and climate activist, suggests the climate movement will not have sufficient numbers if people of colour are excluded; we cannot address the climate crisis unless Black Lives Matter (Johnson, 2020). To be successful, we need the biggest, brightest team there is—the problem cannot be solved with the voice of one demographic. White people, often overrepresented in the environmental movement, have regularly seen climate change as a more important issue than racial justice, and therefore exclude people of colour from their work (Heglar, 2020). Additionally, BIPOC (Black, Indigenous, and People of Colour) women are battling White supremacy and the patriarchy simultaneously with the climate crisis. How can they devote time to climate change while living in a system designed to oppress, incarcerate, or disregard specific important segments of the population? How can we ask that BIPOC folks commit themselves to the crisis with White supremacy standing in the way? Racism thwarts efforts to address climate change because it successfully distracts, drawing attention from one crisis to another. We need to remove barriers so that everyone is welcome at the climate solutions table, because not only is everyone worthy of a seat, but everyone is essential.

Better Solutions for All

Reducing inequities is imperative, not only so that those who have been marginalized fare better through the climate crisis, but also because those who have been closest to climate impacts are the ones who have the solutions. Women and BIPOC communities are disproportionately impacted by the climate crisis. Women worldwide are increasingly likely to experience gender-based violence during and after extreme weather, as well as during prolonged drought and food scarcity (Alston, 2013). Ice melting drastically impacts the time that Inuit communities can be on the land, reducing time spent visiting other communities, fishing, foraging, hunting, and trapping, and this impact on the landscape and their cultural traditions results in a deep sense of loss (Willox et al., 2015). Black Americans experience the brunt of climate catastrophes such as Hurricane Harvey and Katrina. Communities of colour are often situated in floodplains and lack green space to absorb water (Frank, 2020).

Due to their disproportionate experiences of climate change and colonial violence, Black and Indigenous women have been organizing social and environmental justice work for decades in order to protect themselves, their communities, and the land (Waldron, 2018). This practice of resistance and resilience is what we need to address the climate. Young women, in particular, are making their own climate solutions tables: Autumn Peltier, Mari Copeny, and Greta Thunberg are representative of thousands of youth striking and sacrificing their education, advocating for clean water, and fighting to protect Mother Earth. Further, Indigenous peoples have been living harmoniously with the land since time immemorial, meaning not only that it can be done, but that those who know how are living all over the world, ready to be listened to as stewards of the earth. Whether it be protecting the Sipekne'katik River from the brine discharge pipeline (Waldron, 2018), saving the Amazon forests (Nenquimo, 2020), overcoming voter suppression to elect a president with a climate action plan (Scanlan & Robinson, 2020), or school striking (Boulianne et al., 2020), the passion, knowledge, and leadership of women and BIPOC people across the world is what could save Earth.

Similar Systems and Structures

We cannot separate issues of racism, misogyny, and climate change. Waldron (2018) argues that we must move beyond discussion of industry causing environmental degradation, and toward how these issues are interconnected. The interconnection of these issues begins with legacies of enslavement, labour, and colonization. The intention of European colonists was to dispossess Indigenous peoples of their land so that colonists could extract resources and exploit land with the use of enslaved African and Indigenous peoples (Elliott & Hughes, 2019). As a result of this, Black and Indigenous people have suffered and continue to experience extreme violence, death, and injustice, while at the same time their labour and land was used to set the stage for global industrialization and the beginning of the fossil fuel era—which continues to warm planet Earth (Costello et al., 2009; Delaney, 2020; Waldron, 2018). Although these events took place generations ago, modern industry continues to use fossil fuels and harm the same populations. For example, today, resource extractive industries often set up "man camps," where mostly White men live in temporary homes near the construction sites at which they work (National Inquiry into Missing and Murdered Indigenous Women and Girls [NIMMIWG], 2019). These camps significantly increase violence against Indigenous women, girls, and Two Spirit people (NIMMIWG, 2019). This extractive system simultaneously pillages the planet's resources and perpetrates violence against Indigenous people. Dismantling systems of harmful resource extraction not only tackles climate change, but also protects BIPOC women.

While it may be possible to reduce greenhouse gas emissions without addressing systems of oppression (for example, by producing electric cars), if we do not change the exploitative system at its core, we risk missing our chance at truly respecting the planet in a way that is sustainable for everyone. What kind of world would you like to live in after we have saved the planet? One that is safe from climate change but not police brutality and colonial violence? Or one with health equity, cultural sharing, and peace? To save the earth from mass extinction, we need to dismantle inequities and centre the voices of women, specifically, Black and Indigenous women and women of colour.

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Research Article

Assessing the Representation of People of African Descent on Nova Scotia's Community Health Boards

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Abstract

According to the Health Authorities Act (Section 62), Community Health Boards (CHBs) in Nova Scotia are intended to "contribute to health-system accountability by facilitating an exchange of information and feedback between the community and the provincial health authority." The present situation, however, is one in which health boards may not represent the demographic diversity of the community. This challenge may be particularly prevalent within African Nova Scotian communities. This paper will quantify whether people of African descent who serve on CHBs match the demographics of the community and discuss whether any discrepancies may affect policy initiatives within Nova Scotia Health. To answer these questions, we conducted a demographic analysis of 31 CHBs. The representation of African Nova Scotian participants on CHBs (5%) exceeds their representation within the total provincial population (2.4%); however, by removing the Southeastern Board, the representation of African Nova Scotians mirrors their representation in Nova Scotia as a whole. African Nova Scotians are overrepresented, to some extent, on CHBs. This overrepresentation is a factor of small sample size and skewed distribution. Even in historically African Nova Scotian communities like the Southeastern Board (with 85% of residents identifying as African Nova Scotians), the board demographics do not match the demographics of the communities they serve. Given the unique challenges African Nova Scotians face within Nova Scotia's health system, representation on all boards may be necessary. The challenges of robust engagement of marginalized communities could be addressed by dedicated recruitment efforts by Nova Scotia Health. Further, the lack of demographic information collected by either CHBs or by Nova Scotia Health presents an inability to address critical concerns within the African Nova Scotian community.

Assessing the Representation of People of African Descent on Nova Scotia's Community Health Boards

According to Nova Scotia's Health Authorities Act, Community Health Boards (CHBs) are advisory organizations designed to provide input on "local perspectives, trends, issues and priorities, and to contribute to health-system accountability by facilitating an exchange of information and feedback between the community and the provincial health authority" (*Bill No. 1*, 2014, Section 62). They play a role in health promotion and allocate funding to local community groups via the NSH Wellness Fund (Nova Scotia Community Health Boards, n.d.). CHBs must have a minimum of nine members and a maximum of 15, unless otherwise prescribed by regulators (*Bill No. 1*, 2014, Section 64). To become a member, individuals must apply online through a Government of Nova Scotia portal. Once the application is submitted, the appointment process is conducted by the Chair of the Board through an open and transparent selection process prescribed by the regulations (*Bill No. 1*, 2014, Section 65).

Through appointments prescribed by Minister of Health and Wellness, CHBs are designed to be a mechanism to increase accountability, transparency, and system responsiveness to local perspectives (Nova Scotia Community Health Boards, n.d.). Boards are not responsible for adjudicating individual patient care concerns, nor do they govern or manage the delivery of health care services (*Bill No. 1*, 2014, Section 63). In theory, CHBs operate as a linkage between grassroots concerns and departmental policy priorities. In practice, however, this mechanism is not clear-cut. Patient-oriented practices, which will be referred to as public engagement throughout the rest of this paper, must reflect the needs of the government, provincial economic conditions, and the community it represents at the same time—all of which are fluid. The selection of non-professional representation in health policy is neither objective nor apolitical. Instead, existing power structures within the domain of health care services can privilege specific points of view, and silence others.

Scholars conceptualize public engagement as a planning apparatus for consultation to better improve specific systems (like health care), not deliberative practices as a whole (Coglianese, 2002). This perspective argues that "consultation" is a government technique used to collect public opinion on pressing political and policy issues (Fitzgerald et al., 2016; Reddel & Woolcock, 2004). It is impossible to improve the system without learning from those who utilize it. Learning from citizens, however, does not necessarily mean improving democratic practices (Adams, 2004). Public engagement is a method of collecting opinions on the administration of public services rather than including those participants in the internal workings of governance. Engagement becomes the only formal means for communities to influence policy deliberation and a foundational component of decision-making (Vigoda, 2002), but not of democracy. Ideally, policy outcomes through consultation reflect the needs, values, and demands of multiple stakeholders on particular issues (Lewis & Kouri, 2004).

While some authors acknowledge the importance of public opinion when evaluating citizen engagement practices, they also consider governmental accountability to be of equal importance when considering its success as a planning apparatus (Abelson & Eyles, 2004; Armstrong, 2009). Rowe and Frewer (2004) argue that public engagement techniques are not democratic because the government is not obliged to utilize public experiences in participation to improve the planning apparatus. In this understanding, citizen engagement is merely about listening to participants explain their experiences rather than making them equal partners in decision-making. In the absence of accountability, citizen engagement techniques do not function for the public but rather for the government (Rowe & Frewer, 2004).

When considering citizen engagement as an instrumental function for better health policy outcomes, one must evaluate how effective it is in the design or redesign of policies and processes. Systems of measurement, or the effectiveness of practices, play a fundamental role in public attitudes toward citizen engagement (Abelson & Eyles, 2004). From the democratic point of view, some authors argue that policy outcomes alone do not reflect the success of citizen engagement as a co-operative planning apparatus (Rowe & Frewer, 2004). Rather, the success of citizen engagement is measured through the public's attitudes toward the process (Adams, 2004). In this sense, the legitimacy of the "output" has nothing to do with policy, but rather the impressions of the participants and the broader community (Schmidt, 2013). Halvorsen (2003), for example, views citizen engagement's success and the success of the state agency itself, as being dependent on the positive experiences of citizens within the process. The author concludes that governmental bodies can reduce citizen discontent toward specific policies by using high-quality participation that satisfies the consumers and improves experiential systems (Halvorsen, 2003). In specific cases, positive experiences in citizen engagement can transform negative opinions toward public deliberation and consultation. By improving citizen experiences with engagement techniques, the state becomes the benefactor of public attitudes both in improving flaws in administration of services and legitimizing governance choices (Hurley et al., 1994). Notably, however, this shift in public attitudes does not necessarily lead to effective governance.

History

A scan of the history of CHBs indicates the disjuncture between this ideal type of citizen engagement and the realities of co-operative governance models. During the 1980s and 1990s, most provincial governments in Canada began implementing regionalized plans for health care administration (Hurley et al., 1994). Many authors, such as Armstrong (2009), have come to understand the process as a means of integrating health care services for cost containment while also responding to the needs of local communities (p. 97).

In 1994, the Government of Nova Scotia, headed by the Liberals, began significant efforts to regionalize health care administration. An internal review of health care entitled *The Blueprint for Health System Reform* dealt with a wide range of issues in health reform and concluded that a new format for health care governance was necessary, as the system in place was neither fiscally responsible nor accountable to the communities it served (Minister's Action Committee on Health System Reform, 1994). The report recommended that CHBs have the authority to determine policy, budgetary, and management decisions (Black & Fierlbeck, 2006), outside the existing traditional top-down model of administration into citizen engagement capacities. Though the report stated that CHBs should have autonomy in budgetary decisions, when they were legislated in 1996, the government restricted the authority and scope of the boards (Clancy, 1997). Instead, the responsibility of CHBs shifted from planning and managing health care administration to consulting duties (Department of Health, 1996). In practice, the government enhanced the role of administrators and reduced the mandate of CHBs.

Public Engagement and People of African Descent

Having diverse representation in leadership positions, especially within the health system, is cited as a social good that could assist in improving the quality of health services (Etowa & Debs-Ivall, 2017, p. 277). Research from the not-for-profit sector shows that diverse boards are more creative in their decision-making, have superior financial performance, and show increased responsiveness to their clients (Bradshaw & Fredette, 2013, p. 1112). Research in electoral behaviour indicates that racialized candidates are more likely to run for office if approached by a racialized local party president (Tolley, 2019). The example demonstrates the importance of descriptive representation in facilitating further leadership and engagement among racialized communities.

Health institutions, however, are perceived by those working within them to do little to address deficits in descriptive representation among their leadership (Etowa & Debs-Ivall, 2017, p. 284). They opt instead to focus on fostering cultural competence among frontline staff, which does little to address the development of diverse institutional leaders (Etowa & Debs-Ivall, 2017, p. 288). Moreover, as Chung et al. (2012) show, members of marginalized communities are less likely to participate in community representational processes in health decision-making due to a lack of trust in the process of selection, and a lack of feeling heard (p. 1653).

Despite being the largest racialized community in the province, African Nova Scotians continue to be under-represented in civic life. The Commission on Effective Electoral Representation of Acadians and African Nova Scotians (2018) notes that the dispersed nature of communities of African descent in the province means that they are typically excluded from representation in the legislature without electoral mechanisms designed to account for this challenge (p. 6). African Nova Scotians are also suffering from a lower age-adjusted employment rate relative to the overall population, which, as One Nova Scotia highlights, reflects systematic challenges to labour market attachment and employment (One Nova Scotia, n.d.). This employment rate, despite One Nova Scotia's best efforts, is not improving (One Nova Scotia, n.d.).

A lack of representation of marginalized communities in socio-political systems is an indicator of social exclusion. It contributes to "the dispossession and devaluation of social and cultural capital" among communities (Gingrich & Lightman, 2015, p. 101). For marginalized community members from racialized minorities, this form of social exclusion is symptomatic of the existence of structural racism throughout our society (Galabuzi, 2012). People of African descent across Canada, and indeed in Nova Scotia, are often bestowed a racialized outsider status that removes them from Canadian society, which includes political representation. These communities suffer from high levels of poverty and unemployment, housing discrimination, and a higher likelihood of proximity to waste and landfill facilities, toxic dumps, and pollution (Waldron, 2016; Maynard, 2017; Wane, 2005).

With these challenges in mind, a useful indicator of the strength of our health system and its capacity to account for the experiences of people of African descent in Nova Scotia, may be their representation on CHBs. Bradshaw and Fredette (2013) found that, among non-profit boards in Canada, ethnic diversity remains low despite the representation of women being comparatively high relative to the overall population (p. 1126). The determinants of this diversity were, in their view, macro-contextual, being impacted by the composition of the overall community (Bradshaw & Fredette, 2013, p. 1127). Chung et al. (2012) found that, among those interviewed in their study of desired characteristics of community representation, the core characteristics deemed to be significant were responsiveness and empowered inclusion (p. 1658). CHBs, if working effectively, ought to provide an opportunity for those marginalized within Nova Scotia's health system to demonstrate these characteristics.

Objectives

This paper seeks to quantify the descriptive representation of people of African descent on CHBs in Nova Scotia. This quantification may indicate the inclusion or lack thereof of people of African descent in public engagement processes across the province.

Hypothesis

H1: African Nova Scotian representation on CHBs will be less than or equal to the community's proportion of the population of Nova Scotia.

Null hypothesis: African Nova Scotians will be overrepresented on CHBs relative to their proportion of the population of Nova Scotia.

Methods

Located across Nova Scotia, CHBs are intended to represent the localized needs of each community in the province. Broken into four zones – Eastern (Cape Breton); Northern (St. Lawrence area); Western (South Shore); and Central (Halifax area) – each zone consists of between seven and eleven boards. We contacted the Nova Scotia Department of Health and Wellness in early September 2019, and asked them for the demographic makeup of CHBs. The Department of Health and Wellness forwarded our request to the Public Engagement and CHB Support division of Nova Scotia Health, which told us to contact the CHBs directly, as Nova Scotia Health did not collect demographic information from CHB members.

We visited each of the 37 CHB social media pages to see if they had their membership listed, and 29 of the 37 did have a membership listing. We then visited their publicly accessible social media pages to find their relevant demographic information (gender, African Nova Scotian or not). We contacted the eight CHBs that did not have a public listing of their membership. Two CHBs responded with their membership listing, and six did not respond to comment. Of these six, the Halifax Community Health Board did not respond with their membership listing. This is a significant limitation to the research due to the historic African Nova Scotian population located within the Halifax region.

Results

Of the 37 CHBs, data was collected on the membership of 31 boards. As noted in Figure 1, boards marked with a "+" sign indicates that membership for multiple boards was reported in a lump sum, affecting nine boards in total. "Truro +" indicates CHBs from East Hants, North Shore, South Colchester, Truro Area, and Along the Shore; "Pictou +" includes Pictou West and Central/East Pictou; and "Digby +" includes Conseil de Santé de Clare and Digby Area (Nova Scotia Community Health Boards, n.d.).

Results reported spanned from 2017 to 2019, with room of variance depending on the frequency of membership updates. Of the 31 CHBs analyzed, there were a total of 287 members: 218 participants identified as female (76%) and 14 participants were African Nova Scotian (5%). As a comparison, in the total

Figure 1

Nova Scotia Community Health Board Demographics (2017-2019)

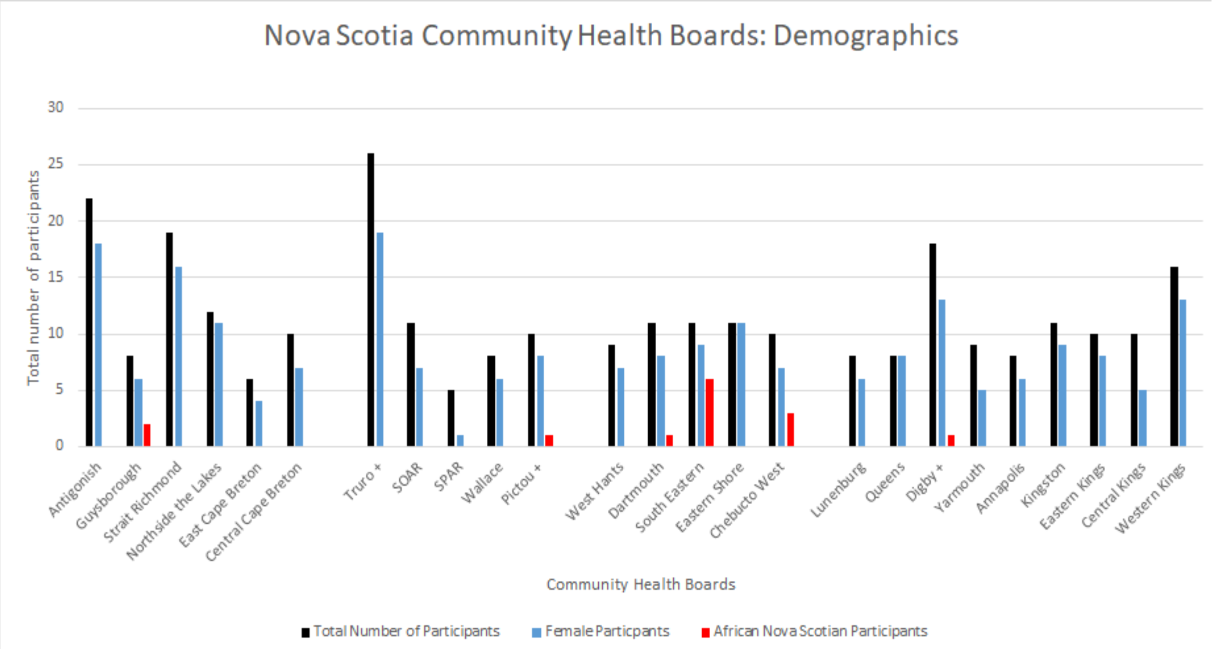
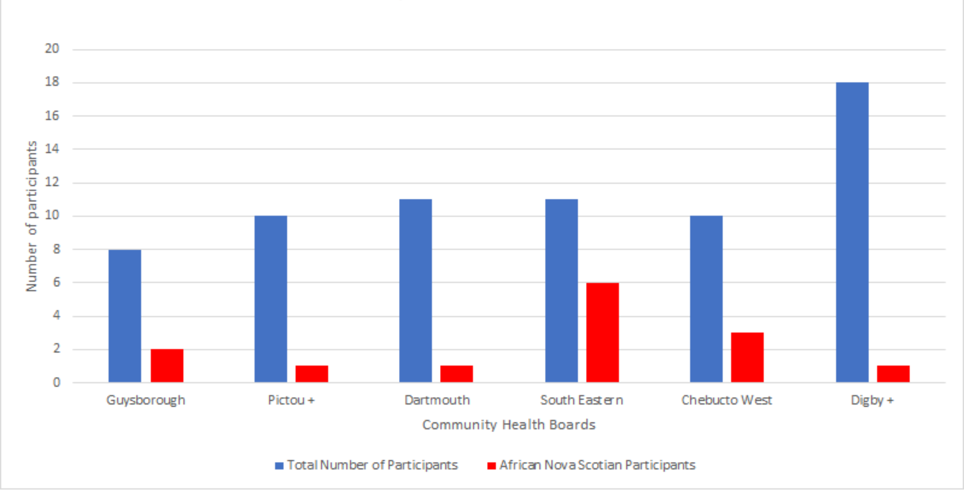


Figure 2

Nova Scotia Community Health Board African Nova Scotian Membership

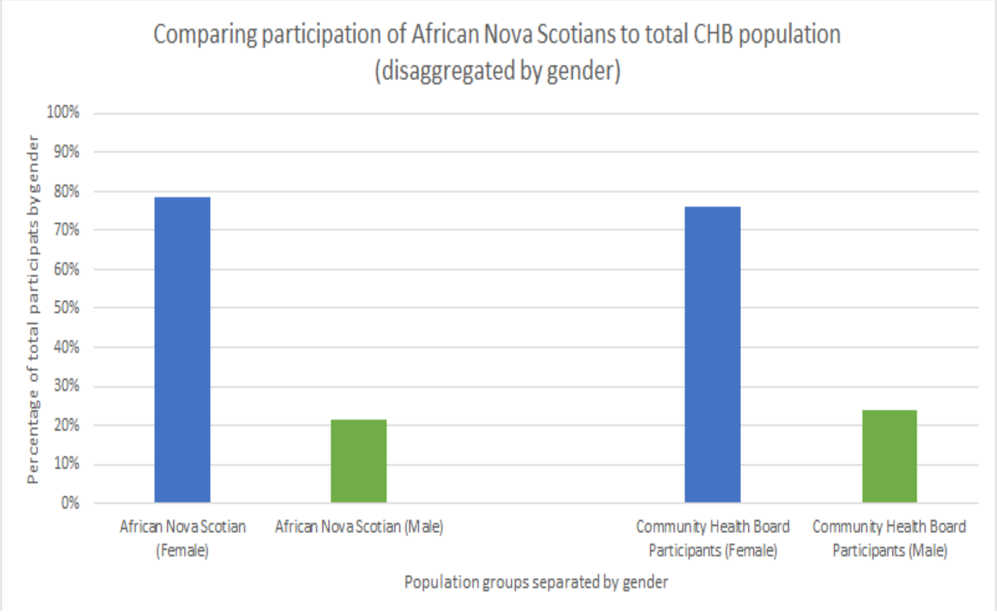


population of Nova Scotia, 51% of residents are female identifying and 2.3% are African Nova Scotian (Statistics Canada, 2016).

In relation to African Nova Scotian participants, although the rate of engagement is above the overall population, these numbers are dependent on the geographic location of the CHB. Only six CHBs reported having African Nova Scotian participants, and all have historic ties to African Nova Scotian populations. For example, the Southeastern CHB has higher levels of African Nova Scotian participants (55%) than any other region. The Southeastern CHB includes populations from North Preston, East Preston, and Cherry Brook, whose residents are roughly 85% African Nova Scotian, making these communities the oldest and largest African

Figure 3

Nova Scotia Community Health Board Gender Demographics

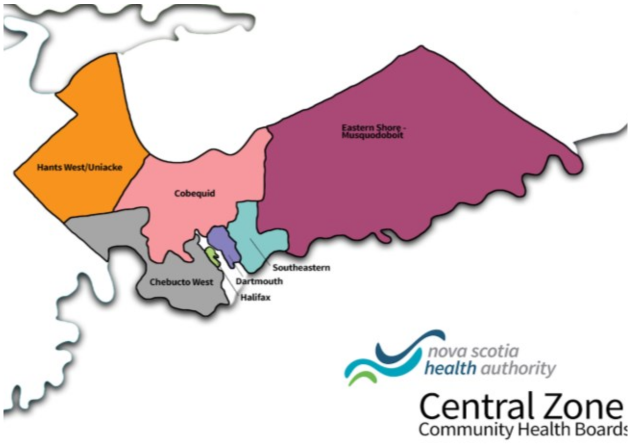


Canadian communities in the country (Kisely et al., 2008, 653).

Finally, we compared rates of African Nova Scotians disaggregated by gender to those of the total CHB participant population disaggregated by gender. We see similar rates of participation among African Nova Scotian women as we do within the total population of female CHB participants (78% to 75%).

Figure 4

Map of Central Zone Community Health Boards (Nova Scotia Community Health Boards, n.d.)



Discussion

Our results indicate that we should fail to reject the null hypothesis, with some small caveats. With 5% total representation on CHBs, there is an overrepresentation of African Nova Scotians on these public engagement bodies. Importantly, however, the bulk of that representation occurs in one CHB: Southeastern. The area that the Southeastern CHB encapsulates includes the following: North Preston, East Preston, Mineville, Cow Bay, Eastern Passage, Lake Loon, Cole Harbour, Lawrencetown and Cherry Brook. If we exclude the Southeastern CHB, the rate of African Nova Scotians relative to the general population is eight members out of 276, or 2.9%–a similar number to the representation of people of African descent in Nova Scotia. Maintaining consistent rates of African Nova Scotian representation relative to the overall population presents a challenge for participation. As noted by the Commission on Effective Electoral Representation of Acadians and African Nova Scotians (2018), the relatively small population of African Nova Scotians compared to the total population of the province means that these communities have little capacity for political influence.

A similar dynamic could be at play within CHBs, where African Nova Scotian representation, excluding the Southeastern CHB, does not constitute a majority on any board, and only occurs on five of the 31 CHBs that responded. A scan of the citizen engagement literature indicates that, wherever possible, particular attention ought to be paid to marginalized communities, whose interests are unlikely to be represented in other ways (Howe, 2011, p. 24). In the CHB context, this attention may be overrepresentation of African Nova Scotians to better reflect community concerns, specific recruitment efforts aimed at attracting African Nova Scotian volunteers to CHBs, or a scan of barriers that interested community members experience in trying to participate in community processes.

Focusing on the Southeastern CHB in particular also provides potential insights into the efficacy of CHBs in predominantly African Nova Scotian communities. As noted above, the communities of North Preston, East Preston and Cherry Brook have the highest proportion of African Nova Scotians of any area in the province, with approximately 85% of the total population of the area identifying as African Nova Scotian. The Southeastern CHB, meanwhile, has six of 11 board members who are African Nova Scotian—a rate of 55%, which is 30% lower than representation within these communities. As Kisely et al. mention, these communities are disproportionately impacted by diseases such as diabetes, hypertension and psychiatric disorders, and seek out specialist mental health services less than the general population (2008, p. 656). The discrepancy between these numbers could reflect broader representation from communities such as Cole Harbour. It could also indicate, however, a lack of mobilization within that community to engage in this particular health board's activity. The efficacy of CHBs in enhancing social and health-related well-being can only be adequately assessed through persistent dialogue among diverse populations. This potential lack of mobilization in the Southeastern CHB, given the health challenges that these communities currently deal with, could be a barrier to more responsive health policy for the area.

Within the data collection process, six CHBs did not respond to requests for demographic information. These were Central Inverness, North Inverness, Victoria, Shelburne—and, most importantly, Halifax and Cobequid. The Halifax and Cobequid CHBs represent a large, diverse population, and their results could change the overall results of this study. Future analyses must ensure the inclusion of all CHBs into the data-sets; however, this can only occur by making changes within Nova Scotia Health. There exists a devolved responsibility onto CHBs to report demographic information to the general public, yet the discretion to respond to inquiries is uneven throughout CHBs. Data collection and distribution must stem from Nova Scotia Health to ensure transparency and accuracy when reporting such information. Further, many CHBs only reported a small number of participants—often well under the criteria threshold of nine, as set out by the Health Authorities Act (*Bill No. 1*, 2014, Section 64). These results indicate two potential causes: A) many CHBs are not meeting the minimum threshold of participants, or B) some of the members on CHBs sit as a "ghost membership", or are registered members who do not actively participate. The phenomenon requires an in-depth analysis.

Conclusion

African Nova Scotians are overrepresented, to some extent, on CHBs. This overrepresentation, however, is a factor of small sample size and skewed distribution. By removing one board, the representation of African Nova Scotians mirrors their representation in Nova Scotia as a whole. This reflection of societal diversity within CHB diversity presents challenges for the democratic engagement of these marginalized communities and could be addressed by dedicated recruitment efforts by Nova Scotia Health. Another critical challenge that emerged from our study was the lack of demographic information collected by either CHBs or by Nova Scotia Health. Demographic information on CHBs must be regulated by the provincial government to ensure that data-sets are reflective of current CHB compositions and accurately portray the diversity within the membership. A study of the efficacy of CHBs to address critical concerns within the African Nova Scotian community is needed to determine best whether these democratic mechanisms are useful, or are simply legitimation mechanisms for state policy initiatives.

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HPJ HEALTHY POPULATIONS JOURNAL

Research Article

African Nova Scotian Grit: A Scholarly Personal Narrative About Nursing Leadership

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Abstract

As an African Nova Scotian (ANS) woman, registered nurse, full-time doctoral candidate and activist, I have decided to share key moments from my experience navigating academia. I discuss how being an ANS woman is significant to this journey as well as the ways in which anti-Black racism reinforces the underrepresentation of Black folks in nursing. The purpose of this scholarly personal narrative (SPN) is to generate meaning from my journey to becoming a nurse leader. The guiding question for this work is: *What is the experience of an ANS woman in becoming a nurse leader?* Guided by Narrative Inquiry and Black feminist theory, my SPN uses the Ten Tentative Guidelines for Writing SPNs offered by Nash (2004). This unconventional approach to research situates stories as the fundamental unit of measurement which emphasizes the significance and meaning of our lives. The iterative approach to this reflective exercise produced two key overarching themes, namely: Developing Personal and Professional Identity, and Potential vs. Power. Each theme contains additional subthemes that capture salient elements of my journey to nursing leadership. This SPN has implications for both education and the nursing profession. For education, this work offers insight to address institutional barriers that perpetuate anti-Black racism. Improving program access for Black students, providing adequate resources to facilitate success and ensuring the representation of Black students, staff and faculty throughout institutions are vital. Likewise, similar insights apply to nursing in the areas of practice, education, research and policy. Specifically, addressing issues of representation and visibility, to foster inclusivity, within the profession is essential.

Nursing leadership, which involves critical thinking, action, and advocacy, exists within all roles and domains of nursing (Canadian Nurses Association [CNA], 2018). Nurse leaders possess knowledge and skills to inspire and influence both people and systems (CNA, 2018). My journey to becoming a nurse leader is a mosaic of challenge and triumph. As a first-generation African Nova Scotian (ANS) university student, I encountered a series of obstacles in my journey to becoming a nurse leader. From an early age, I was reminded that my race, being Black, was undesirable. I did not realize to what extent this would impact how I understood the world. Moreover, I could not have anticipated how influential race would be in my life, especially in relation to my nursing education. As I continue to grow as a nurse leader, I further understand the significance of racism as a social determinant of health. Anti-Black racism, which includes policies and decisions that oppress Black people, is deeply embedded in economic, political, educational, and health institutions (Carruthers, 2018), including nursing. Additionally, anti-Black racism does not exist in isolation and is thus impacted by ableism and heteronormativity, as well as class and gendered oppression (Carruthers, 2018). My experience in nursing has been shaped by oppression. This article is a reflective exercise that analyzes and shares salient aspects of my journey to becoming a nurse leader.

At this moment, I am a registered nurse, full-time doctoral candidate, activist, and mother. I elected to share my story through a scholarly personal narrative (SPN), which is an approach to writing narratives that emphasizes the significance our lives hold (Nash, 2004). SPNs can tell a thoughtful story offering insight into personal and social realities that are often omitted in conventional research (Nash, 2004). My SPN provides a reflective analysis on my experience as an emerging nurse leader by sharing pivotal moments in my nursing education. I believe that sharing my story serves three purposes: expanding the knowledge base by adding stories that have historically been excluded; sharing narratives that resonate with others; and informing policies to promote recruitment, retention, and representation in nursing and post-secondary institutions. While my SPN emerges from a place of vulnerability, there is healing in speaking one's truth. Thus, I use my privilege as an educated Black woman to speak my truth, generating meaning from my experience, through an SPN. The guiding question for this work is What is the experience of an ANS woman in becoming a nurse leader?

Theoretical Underpinning

The theoretical tenets guiding this SPN are those of narrative inquiry and Black feminist theory (BFT). Narrative inquiry uses stories or narratives to describe how individuals make sense of their experience by centring the narrative as the fundamental unit of interest (Clandinin, 2007; Polkinghorne, 1988). Narratives describe human experience and provide an account of a sequence of events with intention to provide meaning (Clandinin, 2007). Similarly, storytelling and oral histories are central to BFT, which is a theoretical perspective that encourages an intentional and unapologetic examination of how intersections such as race, class, sexuality, ability, and gender impact people and groups (Collins, 2000; Lorde, 1984). BFT posits that knowledge is contained within lived experience; thus, to know requires [un]learning about the experience of another (Collins, 2000; Lorde, 1984). [Un]learning about experience involves listening to others as they speak their truth. Speaking one's truth is both an act of resistance and an act of healing. hooks (1993) encourages Black women to be courageous and speak their truth through open and honest sharing that goes beyond simply naming "bad" things or exposing horrors. A commitment to this self-work is essential because "there is no healing in silence" (hooks, 1993, p. 16).

Methods

This SPN employs the Ten Tentative Guidelines for Writing SPNs (Appendix) described by Nash (2004). This approach goes beyond simply recounting a personal story that offers little or no meaning by incorporating methods that are personal and social; practical and theoretical; reflective and public; local and political; narrative and proposing; and self-revealing and self-examining (Nash, 2004). I employed the ten guidelines iteratively throughout the writing process to develop and refine my narrative. Further, I received mentorship from a narrative researcher, Dr. Sheri Price, to conceptualize and create this work.

Findings

The iterative nature of this narrative resulted in an SPN that encapsulates salient moments of my academic experience and development as a nurse leader. The findings of this reflective exercise are presented under two overarching themes with related subthemes. The two main themes are Developing Personal and Professional Identity and Potential vs. Power.

Developing Personal and Professional Identity

Porter (2017) explains that identity development for Black women is based on specific interactions that are connected to and influenced by socialization. Dissecting and examining aspects of my identity has proven useful in understanding how I view issues, problem-solve, and advocate for change. The aspects of my identity that will be discussed below include being ANS, a first-generation university student, and a registered nurse.

ANS Identity

A core aspect of my identity includes being an ANS woman. My ANS identity embodies significant elements of my ancestry in Nova Scotia, which has a profound impact on my nurse leadership and activism. ANSs comprise a community of people within the larger Black community in Nova Scotia, Canada who are descendants of peoples dating back to the 1600s (Whitfield, 2018). Being socialized in a predominantly White environment means that many ANSs were born, raised, worked, and played in spaces that did not welcome or support Black people but rather problematized Blackness. A combination of factors results in an identity, for ANSs, that is both layered and complex and is beyond the focus of this paper. However, despite socialization in an environment that problematizes Blackness, there is deep-seated resiliency, strength, and determination that pushes ANSs to rise against the odds. My ANS identity is further enhanced by my identification as a Black woman. "Being Black" encompasses more than physical features and appearance. Blackness encompasses biological and socio-cultural components as well as a distinct mindset and world view (Carruthers, 2018). This is why many Black scholars, activists, and writers capitalize the word Black when writing about Blackness. Refining this core element of my identity serves as a solid foundation in my nursing leadership. For example, an act as seemingly simple as deciding when to use the term ANS vs. Black is an important decision dependant on contextual factors.

First-Generation University Student

Another significant component of my identity that has influenced my nursing leadership is being a first-generation university student. As the first person in my family to complete high school, attend post-secondary education, and pursue a professional career, it would be an understatement to say that I was not prepared for university. The complexity of being an ANS woman and a first-generation student meant that life beyond high school was a mystery. I was unfamiliar with standard university expectations including reading a course syllabus, academic etiquette, and on-campus student services and supports. Campus orientations were helpful; however, these orientations better served students who had existing knowledge of university processes.

Knowledge gaps about university were compounded by living in an ANS community, where post-secondary education was not the norm. Similar to many ANSs, I was not raised in an affluent community where attending college or university was the norm. Instead, many people in my rural community worked menial jobs or lived paycheque to paycheque. Additionally, I did not have dinner conversations that centred around education or career aspirations. I certainly was not discouraged in these pursuits; rather, conversations tended to focus on more immediate, present-day issues. A lack of career guidance and not seeing myself reflected in higher ranks of society extended into my schooling, where there were few Black teachers or counsellors and even fewer discussions with Black students about future aspirations. Many teachers and staff had low academic expectations for Black students. The absence of early educational advising was countered in large part by Black community members who went above and beyond. Community members, including educators, coaches, and mentors, encouraged us (Black students) and affirmed that we had potential and that we were destined for greatness. Recognizing the implications of first-generation students from ANS communities provides insight for facilitating access and fostering success in post-secondary education.

Registered Nurse

Nursing was not a profession that I considered from a young age. As described, growing up in a small rural community, I did not see any Black folks working in health care unless it was in the cleaning or cooking sector. It never occurred to me that I could be a nurse because I did not see Black nurses. You cannot be what you cannot see. And despite not seeing Black health-care providers, I saw a lot of sickness, disease, and caregiving in my family and community. Chronic illnesses including diabetes and heart disease claimed the lives of too many family and community members. The women in my family cared for sick loved ones, both as they aged and when they died. As a child, I saw home care first-hand: bed pans, bed baths, feeding, and other forms of care. I also saw the ways in which my grandmother, great-grandmother, and great-aunts provided care to loved ones. It was competent, intentional, selfless, and loving. Watching these phenomenal women care for loved ones helped me to truly appreciate what it means to care for another. They were not licensed care providers; however, I witnessed core aspects of nursing care from the women in my family.

My interest in science led me to complete a biology degree after high school. Uncertain about career options with a biology degree, I applied to several community college health-focused programs including a medical laboratory technology program before eventually deciding upon nursing. I was drawn to nursing because the program incorporated a robust scientific curriculum in addition to an accelerated program option for students with science prerequisites. Additionally, my institution of interest offered an entrance scholarship to facilitate access for ANS and Mi’kmaw students. Ultimately, I chose to enrol in nursing for the emphasis on science, the accelerated program, and the renewable entrance scholarship. Becoming a nurse is a culmination of my early childhood experience and interest in science. Witnessing home care first-hand and expanding this knowledge through formal nursing education positioned me to truly embrace the art and science of nursing; I wanted to be a nurse!

Potential vs. Power

The theme of potential vs. power expands upon the systemic barriers that exist in post-secondary education. Specifically, this theme depicts the struggle between personal abilities and capabilities with rigid institutional processes. The subthemes of rising to the challenge, twice as good, self-determination, and contributors to success all further describe the work of countering institutional oppressive standards with tailored initiatives and targeted supports that enhance self-confidence, determination, and eventual success.

Rising to the Challenge

My undergraduate nursing experience was enjoyable, which I attribute to certain key factors. First, as an accelerated student, I had “university experience,” which facilitated organization, balance, and overall success as a student. Second, the accelerated program included a de facto cohort of university-prepared students, which made navigating the program easier. Finally, I completed the program with another cohort of more than ten Black students who, together, built a solid community of support. My undergraduate experience is in contrast to that of my Master of Nursing (MN) program. The ease, confidence, and comfort with which I entered the undergraduate program did not exist at the graduate level. As the only Black student in the graduate program, entering from a position of implied inferiority, I regularly questioned my belonging.

I began the MN program after working at a tertiary maternal, pediatric, and newborn centre. During my clinical practice, I became involved in health policy and research, where I developed a deep appreciation for the ways in which evidence was created and used. My interest to pursue graduate education was supported and strongly encouraged by the research supervisor, who was also faculty within the School of Nursing. With enthusiasm, I began the application process; however, before the submission of my application, I was explicitly told that I did not qualify for the thesis program and that I would only be considered for the course-based or nurse practitioner program. Despite working as a research assistant and showing potential in research, I was told that I could not apply for the thesis-based MN program because my GPA of 3.64 did not meet the 3.7 admission GPA requirement. I did not dwell on this rejection because I was simply excited to be continuing my education. Months later, I was granted admissions to the course-based program: the program to which I was instructed to apply. I was overwhelmed with excitement to embark on this new chapter of my career.

Admissions to the graduate program would not be my only hurdle in graduate school. After time, I realized that my experience and growing potential was no match for the rigid institutional policies that reinforced the exclusion of Black students. Equally disturbing was the discovery that exceptions, through formal and informal processes, are often made. However, this was not an option for me. Instead, the default to rigid and discriminatory policies were prioritized over my personal attributes, experience, and ultimate potential.

Twice as Good

Entering a graduate program as an ANS woman and first-generation university student was no easy feat. Post-secondary education, specifically graduate education, is a privilege that is posited in a way that reinforces inequity. Those who are able to knowingly or unknowingly leverage privilege are more likely to be admitted and succeed. I witnessed and experienced how institutions unfairly place additional burdens on already marginalized students by forcing them into a vicious cycle of needing to be twice as good in order to achieve a fraction of success. To succeed, I had to overcome obstacles that were designed to prevent me from being successful, including restricted admissions, a lack of representative mentors, oppressive curriculum content, stigma, and overt or subtle criticisms of my abilities. The battle to belong goes beyond the default excuse of imposter syndrome. Experiencing institutional racism reinforced by anti-Black policies and decision-making is not the same as doubting whether you arrived at a place by sheer luck. Rather, belonging arises from a belief that you are welcome in a space. Rising to the challenge, time after time, does build character and a supreme level of resiliency. However, it is also an unnecessary stressor that may cause physical and psychological exhaustion. Navigating a space that repeatedly diminishes and dismisses potential and actively attempts to curb success is an all too common experience for many Black students.

An example of this is illustrated by my experience of trying to advocate for equal opportunity. As a course-based MN student, I was not required to take research courses, yet I enrolled in the required thesis courses because I had become passionate about research and was committed to expanding my research knowledge and skills. Toward the end of my first year, I completed the required research thesis courses with a stellar GPA. Recognizing both my interest and potential in research, my supervisor encouraged me to draft a letter to self-advocate for transfer into the thesis program. This inspired me because I felt not only as though my supervisor saw how passionate I was but also that she saw promise in me. So I submitted my request, which was denied. I was told that the program no longer permitted students to transfer into the thesis program. This was disappointing but equally confusing, since the program was normalizing the practice of bridging students from the MN to PhD program. I struggled to understand why non-Black students were identified, selected, and essentially groomed for success, while Black students were being denied admissions into the program or prohibited from doing a thesis-based MN. Again, despite my potential and experience, I was not permitted to enroll in the thesis program. At the time, I believed that there was a valid reason for why I was being denied this opportunity a second time, despite going beyond my program's expectations. I began to believe that I was inferior and that I did not belong. I have since come to understand that my potential was overlooked and dismissed because of factors beyond GPA and outside of my control. My potential was dismissed ultimately because I did not fit the traditional image of a thesis student.

Self-Determination

The struggle to belong as a graduate student regularly challenged my confidence. Despite my effort to "fit in," I felt out of place. I was excelling academically but I still felt as though I did not belong. Ultimately, my perspective began to shift after two pivotal moments: discovering BFT and working in Tanzania. Each of these critical moments enhanced my self-understanding and confidence as an ANS woman. After years of trying to make sense of how I fit into the world, I was suddenly presented with information to which I could relate. Prior to my introduction to BFT, I did not question the status quo; I accepted societal practices, including my own experiences of racism as normal. My Eurocentric education had instilled within me notions of colour-blindness, including the avoidance or dismissal of race and racism. Reading literature by and about Black women was transformative, as it enabled a deeper reflection on my experiences as an ANS woman in education and nursing, while also equipping me with language to articulate and question my experiences.

Travelling to Tanzania and spending three months working at a local university reinforced my growing knowledge from Black feminist literature. After attending a global health conference in 2015, which was made possible by a travel bursary through the Dalhousie Global Health Office (GHO), my passion for global health research was ignited. The GHO was instrumental in my growth as a scholar and this relationship constituted what would become one of the most formative relationships in my graduate education. Accessible travel bursaries and resources for conferences, opportunities in global health work, mentorship, and finally lasting friendships were all elements that accelerated my personal and professional growth. My relationship with the GHO led me to apply for the Queen Elizabeth II Diamond Jubilee Scholarship, which is a federally-funded program that increases the skills of global citizens through international exchange opportunities. This scholarship enabled me to complete my research internship at Muhimbili University of Health and Allied Sciences in Dar es Salaam, Tanzania with a team of Canadian and Tanzanian researchers.

Contributors to Success

Completing my master's degree would not have been possible without specific targeted initiatives and supportive individuals. As a first generation ANS university student, I experienced many of the financial constraints that limit post-secondary education for Black learners including minimal or absent generational wealth, student debt, family obligations, and precarious employment. I was fortunate to receive a scholarship created to support ANS and Mi'kmaw students in graduate studies in conjunction with two named scholarships through the School to cover my tuition and living expenses. Financial assistance in the form of bursaries and scholarships available through dedicated programs was vital. I had accumulated significant student debt from my undergraduate degrees; thus, scholarships alleviated my financial burden and ensured that I could begin and ultimately complete the program.

Financial resources were complemented by supportive individuals and key opportunities for development. For example, the opportunity to strengthen my academic profile through a research internship in Tanzania remains invaluable. Working closely with the team to disseminate research findings through presentations and publications strengthened my research expertise, which continues to inform my nursing leadership. Moreover, working collaboratively and learning from an international research team, with researchers who looked like me, remains unmatched.

Discussion

Representation and Visibility in Nursing

Ensuring representation and visibility of historically marginalized groups in nursing is essential. A legacy of assumptions and restrictions in nursing has reinforced the oppression and exclusion of Black folks (Flynn, 2011). These assumptions include the fundamental image of a nurse, nursing education, and the curriculum, as well as the profession in general. Historical imagery of nurses as angels and handmaidens (Price & McGillis Hall, 2014) combined with restrictions based on race, gender, class, ability, and sexuality are in opposition to how Black people were and continue to be viewed (Collins, 2000; Flynn, 2011). For example, the refusal to admit Black students into early nursing training programs (Flynn, 2011) has congealed norms that continue to perpetuate discrimination throughout nursing. Moreover, nursing education has been described as being oppressive to non-White folks by not attending to intersectionality and attempting to maintain an apolitical position (Bell, 2021). These aspects, among others, have contributed to Black nurses feeling disconnected or marginalized within the profession (Etowa et al., 2009).

Pipeline to Success

Addressing issues of representation and visibility in nursing is connected to larger educational barriers that inadvertently push Black students to be twice as good to simply be considered. Profound barriers are detected in elementary school, with the school-to-prison pipeline. Increased suspensions, excessive detentions, and implicit bias reinforce the disproportionate streamlining of Black students into programs below their capabilities (Bernard & Smith, 2018; James & Turner, 2017). Too many Black students are dismissed as lacking potential, subjected to heightened surveillance and unnecessary scrutinization. These actions have long-term consequences as they reduce the likelihood of high school success, thereby limiting options for continued education and career choice (James & Turner, 2017). Likewise, streamlining Black students into course-based graduate programs has lasting academic and employment implications including decreased funding opportunities, stigma, and career stagnation. Thus, anti-racist frameworks in institution policies and decision-making are necessary to create a pipeline to success.

The Ivory Tower

Entering and navigating academia, popularly referred to as the “ivory tower,” has mental health implications, which are exacerbated by egos, competitiveness, and an elusive work–life balance, among other challenges (Rawlins, 2019). The ivory tower is known to pose unique challenges for Black and Indigenous people and people of colour, whether as students, staff, or faculty. For example, Henry et al. (2017) describe how the under-representation of Black and Indigenous faculty in academia is further strained by work environments that are not equitable, diverse, or inclusive. Growing issues including microaggressions and layered oppression have prompted several institutions to commit to anti-racist initiatives to reduce and attempt to eliminate institutional oppression.

Conclusion

By sharing salient moments from my academic journey to becoming a nurse leader, my SPN offers insight for students, administrators, and decision-makers in nursing and advanced education. As described, I share my story with the intention of normalizing the sharing and inclusion of stories from people who have historically been silenced or restricted within nursing; inspiring others through shared experience; and highlighting persistent barriers in education. Specifically, my SPN elucidates opportunities to address anti-Black racism in academia. For example, challenging restrictive and oppressive admissions processes, improving resource allocation, and committing to positive representation and visibility, are all plausible solutions to position students from marginalized groups for success. The mandate of higher learning institutions should be to cultivate a sense of belonging and create opportunities for the intellectual growth of all students regardless of their circumstance or background.

Finally, this reflective exercise is beneficial in my ongoing nursing practice and activism work. By analyzing pivotal moments loaded with challenges, triumph, self-doubt, and self-determination, I learn more about myself and about the ways in which society works for and against people. Navigating the ivory tower continues to present challenges; however, collaborative efforts with like-minded individuals provide the building blocks to challenge issues, develop sustainable solutions, and transform oppressive norms. My passion for research, commitment to excellence, and desire to see change is what drives me. As an ANS woman, Black feminist, mother, and nurse leader, I will continue to speak my truth and contribute to change.

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Appendix

Ten Tentative Guidelines for Writing Scholarly Personal Narratives (SPNs)

1	Establish clear constructs, hooks, and questions
2	Move from the particular to the general and back again… often
3	Try to draw larger implications from your personal stories
4	Draw from your vast store of formal background knowledge
5	Always try to tell a good story
6	Show some passion
7	Tell your story in an open-ended way
8	Remember that writing is both a craft and an art
9	Use citations whenever appropriate
10	Love and respect eloquent (i.e., clear) language

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Research Article

Development and Implementation of a Facebook-Based Peer-to-Peer Support Group for Caregivers of Children With Complex Care Needs in New Brunswick

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Abstract

Facebook has become an important gathering place for patients and caregivers to exchange health-related information and emotional support, otherwise known as peer-to-peer (P2P) support. Despite widespread use of Facebook groups across various patient and caregiver populations, the use of these groups by caregivers of children with complex care needs (CCCN) has not been previously reported. This paper describes the development and launch of a Facebook group for families of CCCN in New Brunswick, Canada, as well as the plans for evaluation and preliminary findings. The Facebook group was developed in consultation with various stakeholders, including a patient and family advisory council. The following factors were taken into consideration: group characteristics, moderators, language, recruitment, and implementation. The potential impact of the group on perceived knowledge of health services and/or resources and health literacy were assessed through semi-structured interviews with group members. The group, launched in October 2020, has been monitored for a period of 10 weeks for its use by caregivers. The group has attracted a total of 81 caregivers of CCCN, including two moderators. Inquiry-based posts were the most common type of posts made by members. The observed surge in group membership upon implementation suggests the need for additional P2P support platforms for caregivers of CCCN in New Brunswick. Ongoing monitoring and evaluation will determine how the group is used by members and whether it has any effect on health literacy and knowledge of resources and services.

Keywords: peer-to-peer support, social support, social media, children with health care needs

Development and Implementation of a Facebook-Based Peer-to-Peer Support Group for Caregivers of Children With Complex Care Needs in New Brunswick

Caregivers of children with complex care needs (CCCN) often have multiple unmet informational needs and require timely access to services and resources to ensure the well-being of their families (Roche & Skinner, 2009). Accessing this support can be challenging for families that encounter barriers, such as access to primary care or financial aid (Charlton et al., 2017), particularly during the COVID-19 pandemic. Online peer-to-peer (P2P) support groups, defined as online communities of individuals with common lived experiences (Naslund et al., 2016), provide an innovative means of connecting and supporting families. Caregivers of CCCN possess invaluable lived experience and knowledge related to available and effective services and programs; connecting these families together through P2P support has the potential to promote information sharing among a community of patients and caregivers in a safe, secure online environment.

Current evidence on the use of social media-based P2P support groups has relied on content analysis of posts from publicly accessible groups, primarily those of patients with various health concerns (Bender et al., 2011; Farmer et al., 2009). This paper describes the development and evaluation plan of a geographic-specific P2P support group for caregivers of CCCN in New Brunswick (NB), Canada. Facebook will be used as the platform for this group. In this study, CCCN are defined as children with multi-dimensional health and social care needs, who may or may not possess a diagnosis of a recognized condition (Brenner et al., 2018).

Background and Rationale

Children with CCCN present across diverse settings, requiring services from multiple care providers, which can result in significant physical, mental, and emotional pressures on caregivers. These pressures have been further exacerbated by the COVID-19 pandemic, due to increased strain on health and social services (World Health Organization, 2020). Social distancing measures, for example, have led to unique challenges for caregivers of CCCN, leading to increased caregiver stress and loneliness (American Psychological Association, 2020).

Online P2P support offers an accessible and inexpensive source of informational knowledge and emotional support (Rossman, 2007). P2P groups have been shown to provide individuals with valuable and timely informational, social, and emotional support without participants leaving their homes (Cole et al., 2017; Diefenbeck et al., 2017; Partridge et al., 2018). These benefits have been observed in groups of individuals with chronic disease (Partridge et al., 2018), multiple sclerosis (Shavazi et al., 2016), and HIV (Henwood et al., 2016), and caregivers of individuals with chronic illnesses (Diefenbeck et al., 2017; Scharett et al., 2017). The relationships formed through online interactions can result in feelings of community and solidarity (Horter et al., 2014), which can influence a sense of belonging (Anderson & Emmerton, 2016). This is an important consideration for families of CCCN in NB, who have reported feeling socially disconnected from resources that help them meet their child's care needs (Charlton et al., 2017).

Studies focusing on P2P support groups on social media have noted the widespread use of Facebook groups across different types of patient and caregiver populations (Bender et al. 2011, Farmer et al., 2009; Naslund et al., 2016), including families of CCCN. In an exploratory study on the uses of online groups by 18 parents of CCCN, Ammari et al. (2014) noted that caregivers primarily used Facebook for accessing informational and social support. Specifically, parents accessed geographic-specific groups for locally-based support and case-based groups for support related to specific conditions. These findings suggest that geographic-based communities can meet the support needs of caregivers of CCCN; however, it remains unclear how caregivers of CCCN use these geographic-specific support groups and what potential impact that membership might have on meeting the support needs of caregivers. Leveraging existing social media to explore the use of P2P support groups by caregivers of CCCN can provide important insight into the culture of online information sharing and emotional support and how it can benefit and meet the needs of caregivers.

For many individuals, the internet is a critical resource in searching for and locating services, programs, and resources. P2P support can increase knowledge of health-related resources and services (Santelli et al., 1997), which can, in turn, affect health literacy. Health literacy is typically defined as an individual's ability to read and understand health information (Powers et al., 2010). Health literacy is negatively associated with health inequalities, which are impacted by a person's living and material circumstances, as well as socio-economic status (Harris et al., 2015). Improved access to information about available health and social programs can empower caregivers and provide them with confidence when interacting with the Canadian health care system (Jackson et al., 2019). However, it is unclear whether social media-based P2P support can improve knowledge of health-related services and programs of caregivers of CCCN. There is evidence, however, that low caregiver health literacy has been linked to difficulties in navigating the health care system, which can result in fragmentation of care (Fields et al., 2018); this link between low health literacy and patient care has also been observed in parents/guardians caring for a child (Lee et al., 2014).

Despite the benefits that Facebook-based P2P support groups can provide for caregivers, ensuring the retention and success of these groups can be difficult for administrators. According to internal data from Facebook, approximately 100,000 new groups are created every day; however, less than half of these groups (43%) survive past the first three months (Kraut & Fiore, 2014). Research on general Facebook groups has identified specific variables that promote short-term success, such as presence of moderators (Kraut & Fiore, 2014), membership size (La Macchia et al., 2016), privacy (Ma et al., 2019), and established rules (Moser et al., 2017). For example, group administrators can promote the initial success of P2P support groups by posting content and frequently interacting with posts by other members (Booth, 2012; Kraut & Fiore, 2014). However, it is unclear what variables might lead to the overall sustainability of these groups.

Online P2P support groups present an opportunity for caregivers of CCCN to learn about and make sense of the maze of services, programs, and treatments available to them, as well as the overwhelming amount of information provided to them from various sources (DeHoff et al., 2016). It gives families control and presents a safe environment in which to exchange emotional support with peers (Zhao & Zhang, 2017). Facebook, in particular, has been noted as an important gathering place for individuals with health care needs and their caregivers (Farmer et al., 2009); however, there currently exist no active P2P support groups for caregivers of CCCN in NB on Facebook (Kelly et al., 2020). Previous research has suggested that caregivers of CCCN prefer to connect with other caregivers who have similar experiences and live in their geographic area (Ammari et al., 2014; Scharer, 2005); however, the use and perceived benefits of such groups by caregivers of CCCN is currently unknown. Specifically, it is unclear whether a geographic-specific Facebook P2P support group can improve knowledge of health-related services and resources and increase sense of social belonging in caregivers of CCCN. This paper describes the development, launch, and preliminary observations of a Facebook P2P support group for caregivers of CCCN in NB and outlines the plan for evaluation.

Study Objectives and Research Questions

The current research sought to investigate the use of a Facebook-based P2P support group by caregivers of CCCN in NB. This research consisted of three steps: (a) develop a Facebook P2P support group for caregivers of CCCN, (b) assess its use by caregivers of CCCN, and (c) explore potential impacts on knowledge of health services and/or resources and sense of social belonging among caregivers of CCCN. The first section of this paper will describe the development and launch of the Facebook P2P support group. The second section will outline the protocol for evaluation and outline preliminary observations.

Primary Objectives

The primary objective in this research was to develop and implement a geographic-specific Facebook P2P support group, in collaboration with a patient and family advisory council, and investigate its use and perceived benefits by caregivers of CCCN. The following research questions form the basis for this research:

1. How is the P2P support Facebook group used by NB caregivers of CCCN?
2. What are the experiences of caregivers of CCCN who use the Facebook group to communicate with other caregivers of CCCN?
3. In what ways does participating in the Facebook group affect NB caregivers of CCCNs' perceived knowledge of services or resources and sense of belonging?

Secondary Objectives

The secondary objective of this research is to better understand factors that relate to the use of the group. Success of the group will be determined by a consistent level of interaction between members of the group. The following research question was used to explore this objective:

4. What factors contribute to the success or failure of the Facebook group for caregivers of CCCN in NB?

Facebook Group Development

A P2P support group was developed using the Facebook platform, which is a free social media website. The group was developed in response to a needs assessment that found that NB families of CCCN feel disconnected from local resources (Charlton et al., 2017), and an environmental scan which revealed that there are currently no P2P support groups on Facebook for families of CCCN in NB (Kelly et al., 2020). The Facebook group, developed for the purpose of this research, is restricted to screened members who live in NB. The purpose of this group is to facilitate the exchange of informational and emotional support between caregivers of CCCN.

The group was developed in consultation with a team composed of stakeholders from NaviCare/SoinsNavi (NB's patient navigation centre for families of CCCN), the University of New Brunswick, Mount Allison University, and the University of Prince Edward Island. Focus groups were held with NaviCare/SoinsNavi's Patient and Family Advisory Council (PFAC), which is composed of six caregivers of CCCN and one young adult who grew up with complex care needs. Group components were vetted by the PFAC, including the title, description, and membership requirements. Table 1 below presents the final iteration of details published on the group.

Membership Screening

Prospective members are required to undergo a short screening prior to gaining admittance to the Facebook group. This screening consists of two short questions presented to the user when they request to join the group:

1. Do you identify as a caregiver of a child or youth with health care need(s)?
2. Do you live in New Brunswick, Canada?

An additional required question asks prospective members to type "I consent". This question provides users with an explanation of the purpose of the group from a research perspective and provides links to the letter of information and informed consent form:

3. CONSENT REQUIRED: Please read the page at the following link and type "I consent" after reading: https://bit.ly/3mHPSeY

Table 1

Facebook Group Final Components

Component	Description of Component Details
Title	NB Children with Health Care Needs
Description	This group is for parents, guardians, and other caregivers of children and youth with health care needs in New Brunswick. This is a safe place to connect with other NB families and share/learn about local services and resources. It is also a place to find answers to your questions and to help others who are on a similar journey. We welcome anyone who cares for a child/youth with any health care need(s). Please note that this group is developed and managed by NaviCare/SoinsNavi (a research-based patient navigation centre based in New Brunswick) to facilitate the exchange of services and resources between caregivers (e.g., parents and guardians) of children and youth with health care needs in NB. This Facebook group serves as a pilot project to better understand online peer-to-peer support. This means that the group is monitored for use and members will be invited to participate in a research interview; however, the information shared within this group will never be made publicly available or shared outside of the group. This project has been approved by the Research Ethics Board at UNB. The letter of information and informed consent is available at the following link: https://bit.ly/3mHPSeY. By participating in this group and answering the third membership question, you are agreeing to participate in this study. The views and opinions expressed in this group are those of the members and do not necessarily reflect the official policy or position of NaviCare/SoinsNavi.
Privacy designation	Closed group
Language	Bilingual
Moderators	NaviCare/SoinsNavi's PFAC members and patient navigators

Note. French translation of the title and description is provided in the group.

Moderators

The use of moderators was posited to be an important contribution to the activity levels (i.e., success) and long-term sustainability of online P2P support groups (Biagianti et al., 2018). Group moderators currently consist of the NaviCare/SoinsNavi patient navigator, who is a Registered Nurse, and a member of the PFAC. Moderators conduct the following tasks on a daily basis: screen prospective members, monitor ongoing discussions, and provide responses to posts without replies.

The patient navigator provides a novel contribution as a health professional in a P2P support group; however, her role within the group is simply to offer one perspective. The lived experiences of other caregivers provide a rich dialogue and exchange of social support that is only available from someone on a similar journey.

Implementation and Recruitment Strategy

After details related to the group were vetted and approved by NaviCare/SoinsNavi's PFAC, the Facebook group was officially launched on October 5, 2020. Members of the PFAC and research team were invited to review the final iteration of the group. Recruitment of group members started on October 13, 2020, using the following strategies:

- invitation to caregivers enrolled in NaviCare/SoinsNavi, sent by their patient navigator;
- media release to 35 community organizations that support families of CCCN in NB;
- posts made on existing Facebook groups and pages used by families in NB (e.g., car seat safety group, etc); and
- media releases to various digital newsletters and online boards off the Facebook platform.

This recruitment strategy was completed on October 20, 2020. Ongoing recruitment primarily consists of word-of-mouth from group members and advertisement of the group on NaviCare/SoinsNavi's public Facebook page.

Evaluation Plan

Study Design

The Facebook group will be evaluated using a qualitative descriptive design to understand the perceived impact and use of a Facebook-based P2P support group for caregivers of CCCN. Qualitative description is a pragmatic qualitative approach that facilitates obtaining straightforward answers to questions in applied health research (Sandelowski, 2000). A qualitative model was chosen to explore the uses and benefits of a Facebook-based P2P support group absent of preconceived models or restrictions.

Study Population

All members of the Facebook group represent the study population. An online survey and semi-structured interviews will take place with a subset of volunteers from within the group. A survey will be distributed to members through a post on the group's discussion board; participants will be asked at the conclusion of the survey if they are interested in being contacted for an interview. Interview participants are required to have been in the group for a minimum of three months; this length of time is specified to ensure that members have had time to interact with content and members within the group. A total of 50 survey participants and 20–25 individual interviews will be sought beginning in January 2021. These numbers were chosen to ensure membership representation and information saturation.

Data Collection

Group members will be invited to take part in an online survey and interview about their use and experience as a member of the group (Research Questions #1 and #2) and perceived knowledge of health services and resources (Research Question #3). The online survey consists of 15 closed-ended questions (e.g., "Have you learned about any services or resources for children/youth with health care needs in New Brunswick as a result of your membership in NB Children with Health Care

Needs?") and three open-ended questions (e.g., "In what ways has the NB Children with Health Care Needs Facebook group helped you, or can help you, address some of your needs in your role as a caregiver?"). Interview questions were structured based on users' experience of the P2P support group (e.g., "In what ways did you or did you not find that the Facebook group was able to meet your needs or provide needed support?") and its effect on accessibility and knowledge of the health care system (e.g., "How did the P2P support group affect your knowledge of existing health-related resources or services?").

The online survey was created using Qualtrics XM. Interviews will take place using Zoom video conferencing software, using the steps outlined by Lobe et al. (2020) regarding social distancing interview measures, given the current pandemic situation. Zoom was chosen due to previous empirical support for its ease of qualitative data collection, data management features, and security options (Archibald et al., 2019). Content published to the group (e.g., posts, replies, etc) will be regularly collected and organized into Excel to better understand the use of the group by members and moderators (Research Question #1). Specifically, Facebook posts will be labelled according to one of six categories based on the information provided in the post: information, emotional, inquiry, advertising, fundraising, and other (Bender et al., 2011; Farmer et al., 2009). Information posts are those containing information of relevance (e.g., shared academic article or news post). Emotional posts describe posts relating an experience, story, or narrative, often allowing a user to share frustrations or successes. Inquiry posts contain a question or set of inquiries from members; this type of post differs from information posts, in that it is primarily based around a question. Advertising posts include a notice regarding an event or sale of a product, and fundraising posts aim to raise funds for a particular cause. Finally, posts designated as "other" are any posts that do not fit one of the previous five categories.

Factors related to the success or failure of the proposed P2P support group, as determined by membership activity, will be regularly collected throughout the evaluation period (Research Question #4). Specifically, the type of posts (as described above) and associated interactions (i.e., likes and comments by members), as well as date and time of post will be counted and kept in an Excel file on a weekly basis. Other indicators suggested in the literature to promote or hinder activity by members, such as number of administrators, involvement of moderators in discussions, and membership size (Biagianti et al., 2018; Kraut & Fiore, 2014), will be recorded throughout the course of the study period. These factors will be compared to the number of published posts, and corresponding interactions, to determine whether there is an association between changes to the group and higher or lower activity levels. Outcomes will be collected throughout the study period (Fall 2020–Spring 2021) and will be analyzed at the conclusion of the study (Spring 2021).

Data Analysis

Survey results from closed-ended questions will be analyzed in Microsoft Excel. Interviews will be recorded using a digital voice recorder and then transcribed verbatim and managed using NVivo software (version 1.0). Open-ended survey questions and interview transcripts will be analyzed using thematic analysis (Braun & Clarke, 2006; Willis et al., 2016). Content collected from the P2P support group (i.e., posts and replies) will be analyzed using content analysis. Content analysis differs from thematic analysis in that it aims to provide a mixed methods approach to describing a phenomenon (i.e., qualitative coding and use of quantitative counts), whereas thematic analysis provides a detailed and in-depth description of qualitative data (Braun & Clarke, 2006; Vaismoradi et al., 2013).

Risk Mitigation

A variety of risk mitigation strategies associated with the use of online P2P support forums have been identified within the literature. These include monitoring discussion posts to prevent the spread of misinformation, lack of replies, technical problems, and data security (Niela-Vilén et al., 2014). Discussion moderators monitor discussion boards to respond to posts and ensure the validity of information on a regular basis. Moderators are trained using best practice protocols (Schippke et al., 2015), adhering to a guide developed specifically for this project. Specifically, all members are provided with clear rules for participating in the P2P support group, which are enforced by moderators. Members who fail to adhere to rules are asked by a moderator to review the group rules and warned that if they continue to break the rules, their membership will be revoked. Misinformation is clarified in a timely manner by moderators, by providing correct information with appropriate source(s).

Preliminary Observations

At the time of writing this paper (December 2020), the Facebook group (NB Children with Health Care Needs) has been live for a period of 10 weeks. The group has a total of 81 members, two of whom act as discussion moderators. Prior to the development and launch of this group, there were no P2P support groups available on the platform for NB families (Kelly et al., 2020). However, it has become clear that there is a need for such a group by the immediate surge in membership after the launch of the group.

The first six weeks of the group represented a period of intense growth in membership, but little interaction between members on the discussion board. A social media plan was put together by moderators to encourage interaction by members; this resulted in weekly discussion posts that prompt members to answer various questions. Moderators posited that members might have been uncomfortable being the first to post; therefore they reached out to a member of the group to ask if she might be comfortable posting a question. This led to a surge in novel posts by members, predominately inquiry-type posts related to caring for a child during the COVID-19 pandemic and locating resources to support their child. Other types of posts published in the group have largely consisted of shared resources from other pages, such as information about CCCN webinars or information about developmental assessments or therapy. The increase in membership activity levels (i.e., posting and interaction) observed in response to weekly discussion posts by the moderators suggests that pre-existing posts may encourage content publication from existing and new members (Booth, 2012), in turn promoting group success.

At this time, a total of 45 posts have been made in the Facebook group. A total of 17 (37.7%) of these posts were categorized as inquiry-based posts. A further 14 were classified as “other” (e.g., administration update); 11 were information-based posts (e.g., post on an upcoming webinar of relevance); and two were fundraising-based posts.

The moderating team meets on a weekly basis to discuss activity within the group and any concerns that arise. The lead researcher (KK) meets with NaviCare/SoinsNavi’s PFAC on a monthly basis to present updates on the group and receive feedback. This feedback consists of ways to promote group interaction and content, as well as input on the research methods and analysis of the project. Determining the factors that affect interaction between members and ensure the longevity of the group continues to be a challenge in the infancy stage of this group due to lack of data; however, the increase in membership activity level is expected to provide further insight into these factors over time. The online survey will be distributed to members in early January 2021, and interviews will begin in February 2021.

Conclusion

This research aims to explore the use of a Facebook-based P2P support group by caregivers of CCCN in NB. The positive response to the group, as indicated by a surge in membership within only four weeks, suggests a possible need for better support and interaction among caregivers of CCCN in NB. Ongoing monitoring and evaluation will determine how the group is used by members and whether it has any effect on health literacy and knowledge of resources and services.

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HPJ HEALTHY POPULATIONS JOURNAL

Research Article

The Morality of Suicide

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Warning: Please note that some readers may find the following content contained in this paper disturbing due to the sensitive nature of the topic discussed. Reader discretion is advised.

Abstract

The motivation behind attempting suicide ranges from egoistic to altruistic, with societal preconceptions varying significantly between the two. In this ethical review, moralist, relativist, and libertarian theories are utilized to explore the morality of suicide. The hedonistic act utilitarian theory, which assesses the righteousness of an action solely based on the amount of pleasure or displeasure it creates, is used to evaluate the morality of suicide. According to the beneficence principle, there is sometimes a moral justification for suicide to alleviate suffering. On the other hand, Mill's rule utilitarianism views actions by their effect on overall human happiness and directs us to perform actions that maximize utility. For some individuals, like those undergoing immense suffering, the right to painless suicide would maximize utility. Kantian theory focuses on an individual's duty to uphold honour, dignity, and rationality. Collectively, these three virtues set the foundation of Kantian deontology. Furthermore, the libertarian view emphasizes the inherent right of human beings to individual security, liberty, and property with minimum government intervention. Libertarians recognize that suicide can be a rational and reasonable response to intolerable suffering. The ethical theories have proven to be interdependent; together, they propel us toward a better understanding of the morality of suicide.

The Morality of Suicide

Suicide is the 14th leading cause of mortality in meritocratic societies, where an individual's failures are viewed as an irreconcilable existentialist verdict on one's soul (Frey, 1999). Suicide reminds us of the fragility of the human psyche and how self-inflicted psychological torment can lead humanity to the brink of self-destruction (Fisher et al., 2018). Although suicide is often deemed a taboo topic, it is vital to examine suicidal ideation to comprehend the underlying morality (Fisher et al., 2018). The motives behind suicide attempts can range from egoistic to altruistic (Singer, 2003). Egoistic suicide is characterized by a loss in social cohesion and possession of a cynical attitude, consistent with the facets of Western modernity (Szasz, 2002). Altruistic suicide is characterized as a benevolent type of suicide that involves self-sacrifice for the greater good of everyone else (Singer, 2003). The societal preconceived notions of the types of suicide vary dramatically (Beauchamp et al., 2007). For instance, altruistic suicide is often seen as heroic, while egoistic suicide is perceived as dishonourable because an individual refuses to partake in their duty of reciprocity to society (Singer, 2003).

Ethical sentiments toward suicide can be broadly classified as relativist, moralist, and libertarian (Ho, 2014; Szasz, 2002). The relativistic approach evaluates the cost-to-benefit ratio of suicide by accounting for the cultural, temporal, financial, and situational circumstances of the suicidal person under consideration. Whether suicide is deemed acceptable or not depends on the needs of the individual in the context of the situation (Ho, 2014). Rule and act utilitarianism best exemplify the relativistic ethical framework (Feldman, 2006). The central core of the moralist school of thought is the sanctity of life principle, according to which human life is of inherent value regardless of the quality of life lived (Brassington, 2006). Moralism supports the moral obligation to strive for the protection of life and the prevention of suicide. Moralists like Kant have a propensity for deontology, a school of thought that judges the morality of an action based on rules instead of its consequences, and condemn hedonistic egoism (Ho, 2014). The libertarian notions revolve around the indispensability of patient autonomy and non-interference of authority in personal matters (Ho, 2014; Szasz, 2002). Libertarians assert that suicide is the most fundamental right of being a human (Szasz, 2002). In this ethical analysis, the relativist, moralist, and libertarian theories are applied to explore the morality of suicide. The primary inference of this paper is that suicide is permissible only under extenuating circumstances, as supported by act utilitarianism, rule utilitarianism, Kantian deontology, and libertarian theory.

Discussion

Relativist Theory: Act Utilitarianism

The hedonistic act utilitarian theory applies the utility principle impartially to appraise the morality of suicide (Beauchamp et al., 2007; Feldman, 2006; Fisher et al., 2018). Act utilitarianism, as proposed by Bentham, judges the righteousness of an action by the net pleasure or displeasure it produces (Feldman, 2006). The quality of pleasure or displeasure can be ranked by considering the intensity, duration, certainty, fecundity, propinquity, and purity of the pleasure (Beauchamp et al., 2007; Feldman, 2006). Higher displeasures are not driven by our emotional impulses and involve a complex cognitive element (Fisher et al., 2018). In the context of suicide, we ought to resort to the beneficence principle, as there is no pleasure accompanying the act of suicide, but there are ways of curtailing the net displeasure (Fisher et al., 2018). The beneficence principle refers to doing good by reducing displeasure and pain (Feldman, 2006). In cases of suicide, where the net empirical displeasure is minimized, such suicide attempts could be justified (Feldman, 2006). A patient who is suicidal after a terminal illness diagnosis may view their future as bleak, so ending their life may seem like the only way to escape their anguish (Feldman, 2006). An egoistic suicide of that nature may be justified;

however, if the individual has multiple dependents who rely upon them or if their suicide will breed profound feelings of bereavement in immediate family members and friends, their suicide may be impermissible (Beauchamp et al., 2007; Feldman, 2006; Fisher et al., 2018). Empirical, evidential support, as calculated by Bentham's felicific calculus, is required to determine the legitimacy of a suicide (Feldman, 2006). Higher levels of displeasure are reflected in rational, persistent, informed, and voluntary requests to end one's life (Beauchamp et al., 2007; Feldman, 2006). Moreover, a minimized negative impact on society, relatives, and friends all contribute to increasing the permissibility of suicide (Feldman, 2006). In this case, the utilitarian act theory appears to be moderate, holistic, contextual, and personalized.

An implication of act utilitarianism is that suicidality is not necessarily a symptom of mental illness, as obsolete psychiatric literature has had us believe (Beauchamp et al., 2007; Feldman, 2006). Although a significant number of suicide attempts are associated with mental illness, suicidality is by no means a direct sign of mental illness (Ho, 2014). It is important to avoid inculcated, social preconceived notions of suicide, as recourse to such stereotypes of suicide aggravates rather than ameliorates the suicidality of patients (Feldman, 2006). Suicide can be a rational, well-contemplated decision that an informed, psychologically stable individual pursues (Feldman, 2006; Ho, 2014).

The principles of act utilitarianism further suggest that suicidality in the mentally ill is unlikely justified, as a distorted moral agency cannot yield rational, informed, or voluntary decisions (Beauchamp et al., 2007; Feldman, 2006). Additionally, anomic suicides characterized by impulsivity and spontaneity lack a well-grounded basis and are often a significant loss to society, making them impermissible (Feldman, 2006).

Relativist Theory: Rule Utilitarianism

Mill's rule utilitarianism centres around the aggregate long-term consequences of actions by deriving general rules that apply universally (Fisher et al., 2018). An escape from needless and incurable suffering ought to be a viable option for eligible candidates who are motivated by higher displeasures and whose deaths present a limited impact on society, as this ultimately maximizes utility (Beauchamp et al., 2007; Feldman, 2006). A universal rule that allows individuals under extenuating circumstances to complete suicide does not pose any dangers if the appropriate safeguards are followed (Feldman, 2006). Mill's harm principle further substantiates the aforementioned point, as paternalistic restraint is an offence to an individual's liberty (Feldman, 2006; Ho, 2014). The harm principle argues that individuals should be permitted to pursue whatever they please if other citizens are not harmed (Beauchamp et al., 2007; Feldman, 2006). This principle reinforces rule utilitarianism in many regards and precludes repressive dogmas that are ultimately associated with less utility (Feldman, 2006).

Moralist Theory: Religious Stance

One of the most popular moralist viewpoints advocating for the preservation of life is the religious stance that claims that the mere act of suicide is an affront to God, as we may be encroaching upon God's province (Frey, 1999). Whether or not suicide is a violation of God's will is more of a theological argument than a moral argument (Szasz, 2002). Nonetheless, the argument does not hold, due to subjectivism in the interpretation of God's word (Frey, 1999; Szasz, 2002). Allowing someone to complete suicide is as rebellious as saving someone by performing CPR because, in both cases, we may be thwarting God's plan (Fisher et al., 2018; Frey, 1999). If suicide is an interruption of the natural laws, why is saving a life any less of a disturbance of nature?

Alternatively, one can argue that being saved by CPR was destined to happen and that the physician utilized the powers endowed rightly by God without being impious (Frey, 1999). By the same token, we ask why those same endowed capacities cannot be employed to end one's life. This logical incoherence and subjectivity around God's will renders the argument futile and unreliable when investigating the morality of suicide (Frey, 1999; Szasz, 2002).

Furthermore, the religious absolutist stance advocating for the sanctity of life principle is not well-founded and appears overly idealistic (Frey, 1999). The sanctity of life principle claims that life is of intrinsic worth, as it is a gift from God (Frey, 1999; Szasz, 2002). It claims that we have a debt of gratitude to pay, and repaying this debt comes in the form of doing good to others, which requires that we accept the gift of life that has been granted to us (Szasz, 2002). Taking one's life through suicide would be denying God's gift and would exhibit ingratitude (Frey, 1999). However, is life still considered a gift if it becomes unbearable and characterized by irreversible deterioration of health, complete dependency, and extreme anguish? We would no longer have the capacity to care for or benefit ourselves, let alone benefit society in such circumstances (Frey, 1999; Szasz, 2002). Moreover, we would not have the capability to repay the debt of gratitude as we are incapable of contributing to our community, and thus, our life serves no purpose (Frey, 1999). The sanctity of life principle appears to contradict itself when applied to terminally ill patients, and as such, we ought to resort to a more robust systematic moralist stance such as Kantian deontology.

Moralist Theory: Kantian Deontology

Kantian deontology is based on categorical imperatives, where moral duties are unconditional, dispassionate, and impartial (Beauchamp et al., 2007; Cholbi, 2015; Fisher et al., 2018). Moral duties are discoverable by reasoning, and moral credibility is solely determined by the moral will underlying an action. Formulations are central pillars to Kantian theory, guiding sentient beings in making rigorous moral appraisals (Beauchamp et al., 2007; Cholbi, 2015). A related formulation to the discussion of suicide is the respect of personhood formulation, which demands that every individual should be treated as an end in themselves and never merely as a means to an end (Budić, 2018). Many may argue that by completing suicide one opts to renounce their moral agency and thereby relinquishes their personhood by using themselves as a means to an end (Budić, 2018; Cholbi, 2015). Proponents of the anti-suicide stance also use the Kantian self-love principle to explain that suicide is contradictory to self-love and claim that the maxim of suicide can never be universalized without adverse results (Beauchamp et al., 2007; Budić, 2018; Cholbi, 2015). However, Kant's thoughts are more nuanced than critics infer. It is true that Kant generally perceives suicide as defective and as an unnatural way to confront reality, but he acknowledges that sometimes suicide is acceptable (Budić, 2018). Shallow motives behind suicide like unhappiness or despair are unjustifiable (Budić, 2018; Cholbi, 2015), but Kant regards suicide as an acceptable last resort when an individual loses the fundamental virtues that grant life value (Cholbi, 2015).

Kantian deontology revolves around three fundamental virtues that trump the need to preserve biological life (Budić, 2018; Cholbi, 2015). These three virtues are honour, dignity, and rationality (Budić, 2018). Collectively they allow us to pursue a moral existence and imbue us with an absolute moral worth (Beauchamp et al., 2007; Budić, 2018; Cholbi, 2015). A life devoid of such pivotal virtues is of no value (Cholbi, 2015). In the case of irreversible dementia, where patients gradually lose the ability to rationally think and remember, it is difficult to see value in their lives (Budić, 2018; Cholbi, 2015). Rationality gradually decays with the progression of dementia, and with it, dignity is lost as autonomy and self-esteem are unrealized (Cholbi, 2015; Fisher et al., 2018). Honour, which is a social construct, becomes unattainable when the patient is seen as a burden and fails to follow the social code of conduct (Cholbi, 2015). Such an instance where an individual is deprived of honour, dignity, and rationality exemplifies an individual losing their moral agency, while barely clinging onto their biological life (Budić, 2018). An advance directive issued by the patient at the onset of the terminal disease should be provided to ensure the decision is autonomous, informed, voluntary, and rational (Beauchamp et al., 2007; Cholbi, 2015). After all, autonomy is the basis of dignity, and by necessitating an advance directive we would ascertain the patient is treated as an end, satisfying the second formulation of Kantian deontology (Budić, 2018; Cholbi, 2015).

The maxim subject to universalization would be that any individual diagnosed with a terminal illness and either expected to be or currently deprived of honour, dignity, and rationality should have the right to undergo active euthanasia (Brassington, 2006). Such a maxim is unlikely to apply to individuals suffering from terminal morbidities who are content with their life, as satisfaction presupposes some variant of honour, dignity, and rationality (Brassington, 2006; Budić, 2018; Cholbi, 2015). The maxim can be universalized in a subset of the population that qualifies without any foreseeable dire ramifications (Brassington, 2006). There may be some practical limitations when applying this maxim, especially with regard to the administration and method of delivery.

Libertarian Theory: Libertarianism

The libertarian outlook has been adopted in nations where suicide has been decriminalized, where patient autonomy trumps the clinical duties of preserving life (Fisher et al., 2018; Szasz, 2002). Libertarians acknowledge that suicidality can be a rational and reasonable response to intolerable suffering (Szasz, 2002). The principles of individualism and individual liberty contradict the psychiatry practice of involuntary hospitalization, where psychiatrists coercively dominate a patient's life by chemical or physical restraints. Although hospitalization, constant monitoring, and environmental restriction can help in temporarily preventing the patient from completing suicide, these measures are by no means an optimal solution (Fisher et al., 2018; Szasz, 2002). In fact, such extensive measures promote regression and dependency, which opens more doors for oppressive and restrictive interventions (Szasz, 2002).

Libertarian theory treats patients as free agents capable of determining their beliefs and actions while minimizing state intervention. However, patients are often not free agents and are influenced by social and political factors, which obscure or gloss over their genuine needs (Fisher et al., 2018). The overreliance on the patient's judgments may lead us to prematurely euthanize individuals who would have been happier alive, and as such libertarian theory should be applied with caution while continuing to respect patient autonomy (Fisher et al., 2018; Szasz, 2002).

Conclusion

All the discussed ethical sentiments present a compelling account of the morality of suicide in the clinical context. The relativistic stance, as represented by act and rule utilitarianism, highlights how the permissibility of suicide is contingent upon a holistic and contextual moral appraisal. This is best exemplified in Bentham's act utilitarian theory, where the motives are ranked and ascribed points accordingly, while the societal effects are assessed based on impactfulness. Mill's stance reveals how proffering eligible candidates the right to die maximizes utility. On the other hand, the religious stance subsumed under the moralist outlook proves to be flawed due to the logical incoherence and the subjectivity present in the interpretation of God's will. In Kantian theory, the absence of the three keystone virtues leaves an individual without a moral agency and hence a life of no value as exemplified by the dementia case. The derived maxim proves to be universalizable, and respect of the patient's personhood arises in relying on an advance directive that an autonomous, informed, and rational patient formulates at the outset of the terminal morbidity. Lastly, the libertarian stance underlines how suicidality could be a rational response to suffering and how patient autonomy should be held as being of the utmost importance. The main deduction from this ethical review is that suicide could be a rational choice that is completely permissible under extenuating circumstances.

The theories are interconnected, and an amalgamation of the principles of the deliberated theories certainly brings us a step closer to unravelling the morality of suicide. It also appears that as one theory emerges as inflexible and rigid, the other theories compensate, allowing us to develop a more overarching picture. The most fundamental example of this is how utilitarianism compensates for the absence of a consequentialist element in Kantian deontology. The inferences of this ethical analysis should only be accepted prima facie, as there may be other ethical principles unaccounted for here.

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HPJ HEALTHY POPULATIONS JOURNAL

Research Protocol

Improving the Pediatric to Adult Care Transition Experience: Recommendations From Young Adults With Complex Care Needs: A Scoping Review Protocol

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Abstract

With advancements in modern medicine, an increasing number of youth with complex care needs (CCN) survive into adulthood. As service demands increase for this group, challenges exist on how to best facilitate meeting their needs as they transition from pediatric to adult health care. There is growing evidence of young adults describing their transition experiences and suggesting improvements to the design and delivery of these services. By synthesizing the existing literature, an increased understanding can be gained about the recommendations of those who have recently transitioned from pediatric to adult health care, thus improving both patient outcomes and experiences. This scoping review aims to comprehensively map recommendations on how to improve the transition from pediatric to adult health care based on the experiences of young adults (aged 18-30) with CCN. This study protocol outlines a scoping review of peer-reviewed and grey literature, following the Joanna Briggs Institute (JBI) scoping review methodology. Literature will be identified using a comprehensive search strategy developed by a JBI-trained librarian. Papers involving primary studies with recommendations of young adults recently transitioned from pediatric to adult care will be included. Search strategy results will be screened by two independent reviewers and included studies will have duplicates removed and charted according to a modified PRISMA flow diagram. Working with the Centre for Research in Integrated Care at the University of New Brunswick, knowledge translation activities will involve targeted communication channels to a variety of knowledge users, such as researchers, clinicians, and policymakers.

Keywords: pediatric to adult transition, transition experience, complex care needs, scoping review, quality improvement, patient engagement

Improving the Pediatric to Adult Care Transition Experience: Recommendations From Young Adults With Complex Care Needs: A Scoping Review Protocol

Young adulthood (YA) is a complex time when life transition dilemmas arise concerning education, employment, health engagement, and relationships (Al-Yateem, 2012; Cheak-Zamora & Teti, 2015; Vincent, 2017). It is an important life development stage since it "determines the young adult's position within society" (de Jong-Gierveld, 2001, p. 98). Due in part to modern health care advances, a high number of young adults are living with chronic conditions in North America (Cohen et al., 2011; Kaufman et al., 2007; Pinzon et al., 2006). Youth with medical complexities are also more likely to survive into adulthood (Cohen et al., 2011; Kaufman et al., 2007; Wise, 2004). As a result, Chamberlain and Kent (2005) reinforce the urgent need to study and implement effective services for youth transitioning from pediatric to adult care to set them on a path for optimal life outcomes. When health care transition interventions are delivered in a structured and informed way, improvements in patient experience, health care outcomes, and population health can result (Schmidt et al., 2020). A synthesis of research is required to understand the transition process from pediatric to adult care from the perspective of young adults with medical complexities, specifically their recommendations on how to improve transition policies and practices. While youth from this population represent only a fraction of those transitioning from pediatric to adult care, they encounter more challenges with the process, and thus their recommendations may contribute to transition process improvements for other populations (White & Cooley, 2018).

To date, reviews on the transition from pediatric to adult services have largely reported on the experiences of youth through the lens of caregivers and care providers, ignoring the voices of the young adults who have experienced transition in care (Betz et al., 2013; Okumura et al., 2015).

The transition from pediatric to adult care is categorized as the purposeful and planned process that involves the movement from child-centred to adult-oriented care systems (Blum, 2002). This transition process can be challenging for youth with complex care needs (CCN). CCN are defined as "multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. CCN are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by healthcare structure" (Brenner et al., 2018, p. 1647). As a result of these complexities, youth with chronic health conditions are significant users of health care resources (Pinzon et al., 2006). Examples of conditions associated with CCN include diabetes, cerebral palsy, epilepsy, spina bifida, and mental health conditions (e.g., depression, anxiety, mood disorders; Brenner et al., 2018; New Brunswick Health Council [NBHC], 2017). In North America, approximately 15-18% of youth have at least one chronic condition (Arim et al., 2015; Kaufman et al., 2007).

Evidence suggests that improving the transition experience of young adults with CCN is challenging, since this population often faces service provision gaps and barriers to accessing care (Nelson, 2016; Rich, 2017). Understanding the health care experiences of this population is a crucial first step in driving health care improvement (Luxford & Sutton, 2014). White and Cooley (2018) suggest more research is needed regarding health care transitions with a focus on experiences of youth, young adults, and families, as well as examining transition outcomes from a population health perspective. Currently, very little research focuses on the perspectives of young adults with various CCN when making recommendations for improvement in the transition process. To our knowledge, there is no comprehensive review focused uniquely on capturing improvement recommendations of CCN patients from the lens of young adults who have recently transitioned from pediatric to adult health care.

Given the growing body of literature on YA transition, a number of systematic reviews have been conducted in the following transition areas:

- health care for youth with special health care needs (Bloom et al., 2012),
- care of children and youth with type 1 diabetes (Nakhla & Daneman, 2012),
- young peoples' experiences of care from child to adult mental health services (Nelson, 2016; Rich, 2017),
- evaluation of research on adolescents and emerging adults with special health care needs perspectives (Betz et al., 2013),
- continuity of care applications to transition research and clinical practice using the International Classification of Functioning, Disability and Health (ICF) framework for youth with chronic health conditions (Nguyen et al., 2018), and
- meta-synthesis of experiences when transferring from pediatric to adult wards within a hospital setting (Fegran et al., 2014).

The reviews published to date have limited areas of scope, such as focusing only on the outcomes of transition (e.g., adherence; Nakhla & Daneman, 2012), concentrating on transition models or systems issues (Amaria et al., 2011; Nelson, 2016), exclusively focusing on Organisation for Economic Co-operation and Development (OECD) free economic market country settings (Rich, 2017), or being restricted to one patient population or sector (e.g., autism patients in the context of higher education; Vincent, 2017). There is also insufficient inclusion of youths' voices compared to other perspectives such as that of caregivers (Cheak-Zamora & Teti, 2015; Cohen et al., 2018), with the exception of a review by Betz et al. (2013), which includes the perspectives of adolescents and young adults. This review differs from Betz et al. by including current studies that exclusively feature perspectives of young adults who have already experienced the transition process to adult services, rather than significant adolescent representation. Betz et al.'s (2013) study evaluates research on health care transition for youth with special health care needs. The current scoping review will expand on previous reviews and provide an overview of recommendations on the transition process from the perspective of young adults across geographic locations and study types.

The primary objective of this review is to comprehensively map recommendations on how to improve the transition from pediatric to adult health care based on the experiences of young adults (aged 18-30). It is important to study this period of changeover, given that youth experience disjointed and difficult shifts from pediatric to adult care (Hopper et al., 2014). If left unaddressed, this problem will grow rapidly as the number of young adults with CCN continues to expand (Cohen et al., 2018). Results of this scoping review will address a literature gap and inform future research by producing a clear portrait of synthesized evidence related to improvement recommendations for young adults with CCN progressing from pediatric to adult care.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping review (Peters et al., 2020), as it is recommended to use standardized guidelines in the design and reporting of scoping reviews to ensure reproducibility and robustness. A preliminary search of CINAHL, PubMed, and the JBI Database of Systematic Reviews and Implementation Reports was conducted, and no current or ongoing reviews with the same objective on this topic were identified. In brief, the steps within the JBI scoping review framework are the following: (a) defining and aligning the objective and question/s; (b) developing and aligning the inclusion criteria with the objective/s and question/s; (c) describing the planned approach to evidence searching, selection, extraction, and charting; (d) searching for the evidence; (e) selecting the evidence; (f) extracting the evidence; (g) analyzing the evidence; (h) presenting the results; and (i) summarizing the evidence in relation to the purpose of the review, making conclusions, and noting findings

(Peters et al., 2020). The following sections describe in detail how the review will adhere to JBI's approach.

Step One: Defining the Review Question

To align with the study objective, the scoping review will address the following question:

What are the recommendations of young adults (aged 18-30) who recently transitioned from pediatric to adult health care on how to improve the transition experience?

Step Two: Developing the Inclusion Criteria

The inclusion criteria will consider population, concept, context, and types of evidence sources (Peters et al., 2020).

Population

The focus of our scoping review is on the experiences of young adults with CCN who have transitioned from pediatric to adult care. YA will be defined as individuals aged 18-30 years. We will accept various terms used in the literature regarding young adults (e.g., emerging adult, adolescent, young man, or young woman). Studies will be excluded if their descriptions include experiences of young adults under the age of 18 or above the age of 30, given that many young adults enter adult services by age 18, and transition programs worldwide are completed by the age of 25 (Fegran et al., 2014; Got Transition, n.d.; Kaufman et al., 2007; Nakhla & Daneman, 2012; Rich, 2017). The decision to cap the population at age 30 will prevent participant recall bias by avoiding lengthy time since their transfer to adult care. The review is not specific to any CCN condition, sex, ethnicity, or other demographic variable.

Concept

The main study concept is transition experience recommendations from pediatric to adult care. Transition to adulthood from the pediatric system is defined as the "purposeful and planned movement of young adults with chronic physical and medical conditions" (Blum et al., 1993, p. 570), and encompasses emotional, mental, and behavioural health. Recommendations based on these types of transition experiences must be present in the study to be included and be from the perspective of young adults themselves; studies discussing only experiences without any recommendations will be excluded.

Context

This review will consider transition experience suggestions of young adults with CCN in all settings, such as hospital, clinic, or community-based settings, as well as across all health sectors. Studies will be excluded if they focus solely on intra-institutional transfer (e.g., intra-hospital). There will not be any additional exclusion limitations placed on this review, as the intent is to explore pediatric to adult health care transition experiences.

Types of Sources

This scoping review will consider all primary research studies that use a qualitative design. Mixed methods design will only be considered if a qualitative design is included. Systematic reviews that meet the other inclusion criteria will be excluded from the review; however, the references will be hand-searched for relevant articles. Grey literature, such as unpublished primary studies and/or evaluation reports, will also be considered for inclusion in this scoping review. Studies published in English, and from around the world, will be considered for inclusion.

Step Three: Developing the Search Approach

The search strategy follows a multi-phase approach and will aim to locate both published and unpublished primary studies. During the first phase, an initial limited search was conducted in MEDLINE (Ovid) and CINAHL (EBSCO) to identify text words in the titles and abstracts as well as index terms from relevant articles. During this process, a librarian (AG) developed a full search strategy for MEDLINE by testing search terms, and only those that yielded unique results were included. The search strategy was externally peer-reviewed by a second librarian (AM) using the Peer Review of Electronic Search Strategies (PRESS) guidelines

(McGowan et al., 2016). Searches will be conducted using a combination of database index terms and text words, limited by title/abstract. English language limits will be applied; publication date will not be limited. A full search strategy for MEDLINE (Ovid) is provided (see Appendix A). A final search strategy will be adopted for each database.

Step Four: Searching for Evidence

The databases to be searched include MEDLINE (Ovid), CINAHL (EBSCO), PsycInfo (EBSCO), and Embase (Elsevier). A process to locate sources of unpublished studies and grey literature will be developed using best practices (Bonato, 2018). This will include searching the first 10 pages of Google and Google Scholar, and using relevant keywords to search Dissertations and Theses (ProQuest), institutional repositories, and relevant conference proceedings.

Step Five: Selecting the Evidence

Following the search, all identified citations will be collated and uploaded into the EndNote citation manager with duplicates removed. Titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria using Covidence review management software. Next, the full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the scoping review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion between the two reviewers, or with a third reviewer when needed. Relevant reviews will be tagged within Covidence to search their reference lists. The reference lists of all included studies will be hand-searched for additional studies. The results of the search will be reported in full in the final report and presented in a modified Preferred Reporting Items for Systemic Reviews and Meta-analyses (PRISMA) flow diagram (Tricco et al., 2018). Any deviations from the study protocol will be tracked and reported in the final manuscript.

Step Six: Extracting the Evidence

Data will be extracted from included papers by the two independent reviewers using a Microsoft Word data extraction tool developed by the reviewers. Extracted data will include specific details about the population, concept, context, study methods, and key findings relevant to the scoping review objective. A draft of the extraction table is provided (see Appendix B). This will be modified and revised as necessary during the extraction of included studies. Modifications will be detailed in the full scoping review report. Any disagreements that arise between the two reviewers will be resolved through discussion, or with a third reviewer as needed. Authors of research articles and other sources of literature may be contacted to request additional or missing data where needed.

Step Seven: Synthesizing the Evidence

Data extracted from included papers will be presented in a tabular form (Peters et al., 2020). The table will feature results (e.g., specifying participant subgroup conditions and improvement recommendations, year of publication, research methods, and study purpose). Data will be synthesized based on types of recommendations (e.g., health service need) which will then be pulled together into corresponding themes using qualitative content analysis. Results will be categorized under recommendation types (e.g., service delivery program) accompanied by a clear explanation of classification criteria.

Step Eight: Presenting the Results

The data extracted from relevant published and unpublished literature will be presented in a tabular form that is aligned with the objective of this scoping review (e.g., recommendations). Data displayed will include the author and year of publication, country of origin, type of literature, research design, methods, population(s), sample size, setting, sector, and transition recommendation(s).

Step Nine: Summarizing the Evidence

A narrative summary will accompany the tabulated data and will describe how the results relate to the review objective and question.

Patients and Public Involvement Statement

Patient opinions from a local advisory group will be consulted to design a collaborative strategy for disseminating finding results.

Results/Discussion and Dissemination

This scoping review aims to expand transition improvement research by synthesizing recommendation evidence from young adults with CCN as experienced by those already transitioned. Further insights into patient suggestions on improving their care will be uniquely captured in this process. To our awareness, this is the first scoping review to focus on capturing the improvement recommendations of patients who have CCN from the perspective of young adults who have recently transitioned from pediatric to adult health care. A limitation of this review is that it will not assess studies for quality; scoping reviews do not involve assessing included studies for measures of rigour (Peters et al., 2015). Also, limitations may exist regarding the number of databases searched and will be addressed by explicitly acknowledging that searching other databases may have identified additional relevant studies. Searching four subject databases will help address selection bias, and database selection was guided by the topic. A search of the grey literature will also be conducted to identify additional articles. The search strategy consists of terms appropriately describing the research question, and was peer-reviewed by another JBI-trained librarian. Due to limited resources for translation, articles published in languages other than English will be excluded.

Furthermore, by not having inclusion or exclusion criteria restrictions on specific young adult conditions, sex, ethnicity, or other demographic variables, study results will be of interest to readers from various health backgrounds and disciplines.

Recommendations

Recommendations from young adults can guide knowledge users, such as researchers, clinicians, and policy-makers, toward overcoming health transition service inequalities. Synthesizing recommendations from youth with a variety of chronic conditions has proven a useful tool for policy-makers when addressing health consequences for large populations (Arim et al., 2015). A recent systematic review by Barnert et al. (2019) reinforces the pressing need to develop population health outcome measures (e.g., improving health access) for youth with medical complexities. To fulfill this research need, implications from this review will produce specific ways to improve population health service delivery and indicate key areas for future research directions. Policy-makers from all health sectors involved with transitions from pediatric to adult health care will be encouraged to incorporate results from this review into their quality improvement planning and policy initiatives. Review findings will be disseminated through conference proceedings and a peer-reviewed publication.

Author Note

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Appendix A

Search Strategy: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to September 21, 2020

#	Query	Results
1	exp Chronic Disease/	264078
2	Disabled Children/	6329
3	Health Services for Persons with Disabilities/	109
4	(chronic adj1 (illness or condition* or disease*)).ab,ti.	94483
5	"multimorbid*".ab,ti.	4800
6	(complex* adj3 (care or need* or illness or disease or medical* or condition or health)).ab,ti.	47451
7	"medically fragile".ab,ti.	234
8	"Special health* needs ".ab,ti.	317
9	1 OR 2 OR 3 OR 4 OR 5 Or 6 OR 7 OR 8	388505
10	exp "Continuity of Patient Care"/	246613
11	"transition*".ab,ti.	415396
12	"continuity of care".ab,ti.	6856
13	"continuum of care".ab,ti.	2545
14	10 OR 11 OR 12 OR 13	659764
15	Young Adult/	858967
16	Adolescent/	2036132
17	"young adult* ".ab,ti.	96111
18	"Adolescen*".ab,ti.	281526
19	"youth*".ab,ti.	75624
20	"juvenile*".ab,ti.	82083
21	15 OR 16 OR 17 OR 18 OR 19 OR 20	2624021
22	9 AND 14 AND 21	3458
23	limit 22 to english language	3177

Appendix B

Data Extraction Template

Author(s)	
Year of Publication	
Country of Origin	
Type of Literature	
Research Design	
Study Aim or Purpose	
Population(s)	
Sample Size	
Transition Description	
Transition Recommendation(s)	

HPJ HEALTHY POPULATIONS JOURNAL

Research Proposal

Exploring the Role of Leisure in Immigrant Students' Lived and Embodied Experiences of Identity, Community, and Belonging Within Halifax, Nova Scotia

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Abstract

The Canadian government employs robust efforts to promote and prioritize immigration, as immigration significantly contributes to Canadian economy, population, and culture. As Canada continues to grow as a culturally and racially diverse society, it is necessary to explore and understand immigrants' lived and embodied experiences within community, their sense of identity, and feelings of belonging, as these phenomena can shape health and well-being. Leisure activities or experiences are understood to cultivate and promote self-expression, socialization, and wellness amidst and despite challenges related to resettlement as experienced by immigrants. While there is enough literature about adult immigrants' settlement experiences and the impacts of such experiences on physical, social, emotional, and mental health and well-being, immigrants attending post-secondary institutions are understudied, particularly in Atlantic Canada. Further, the role of leisure in cultivating a sense of identity and belonging is underdeveloped within these contexts. This proposed qualitative study attends to these gaps by exploring the role of leisure in the lived and embodied experiences of identity, community, and belonging as experienced by immigrants attending post-secondary institutions in Halifax, Nova Scotia, Canada. Guided by Merleau-Ponty's principles of embodiment and a transformative paradigm, this proposed study employs collage-making, a creative, participatory method to engage participants and understand their experiences, amplify their voices, and potentially enrich their lives and well-being. Findings of this proposed study can inform policy and practice within post-secondary institutions, settlement services, and community centres, and can deepen our understanding of leisure's potential to contribute to immigrants' identity, belonging, and well-being.

Exploring the Role of Leisure in Immigrant Students' Lived and Embodied Experiences of Identity, Community, and Belonging Within Halifax, Nova Scotia

Immigration contributes to Canada's economy and population, but also to its identity as a multicultural society (Caidi et al., 2010; Reitz, 2009). While Canada benefits largely from immigration in these aspects, immigrants are likely to experience significant resettlement challenges like barriers related to language and communication and lack of social supports, which can threaten their social, emotional, and mental health and well-being (Halli & Anchan, 2005; Tsai & Thompson, 2013; Vahabi & Wong, 2017). Such challenges brought about by change and transition can also lead to social exclusion, isolation, or disconnection from culture or society (Hilario et al., 2015). Thus, immigrants' sense of identity and feelings of community and belonging (Gallant & Tirone, 2017; George & Selimos, 2019) are worth examining. As past research about immigrants' lived experiences in Canada has broadly linked resettlement experiences to immigrants' health and well-being (e.g., Asanin & Wilson, 2008; Hilario et al., 2015), it is imperative to understand how such experiences can also shape immigrants' sense of identity and feelings of belonging within community.

Immigrant youth, ages 15 to 24 (Guruge & Butt, 2015), are increasingly attending university upon resettlement in Canada (Childs et al., 2017) as higher education is associated with greater opportunities for experiencing social and economic integration (Wilson-Forsberg, 2015; Woodgate & Busolo, 2018). In addition, post-secondary institutions can be sites for immigrant students to experience social support (Gagné et al., 2014) and feelings of inclusion and belonging (Selimos & Daniel, 2017). However, immigrant students are more likely than Canadian-born students to experience shifts in their identity and sense of belonging due to challenges that accompany resettlement and migration (Hilario et al., 2015; Woodgate & Busolo, 2018). It is thus necessary to explore immigrant students' experiences within these contexts as immigrants attending post-secondary institutions can experience intense shifts in their identity, as well as social isolation within and beyond school (Selimos & Daniel, 2017; Sica et al., 2014).

Evidence about leisure's role in cultivating identity and a sense of community and belonging among immigrant students attending post-secondary institutions in Atlantic Canada is underdeveloped. Leisure activities or experiences are understood as any freely-chosen activities (e.g., sports, art, or volunteering) that people engage in during their free time or time outside of their obligations, and are understood to provide them with opportunities to experience enjoyment, self-expression, and/or socialization (Caldwell, 2005; Iwasaki & Schneider, 2003; Karlis et al., 2002; Spracklen et al., 2015). Leisure can also have rehabilitative effects for immigrants experiencing isolation or disconnection, as engaging in leisure can foster or rebuild a sense of normalcy for people who have experienced change or disruption (Hurly & Walker, 2019). Thus, a deeper exploration of the role of leisure in immigrant students' identity, community, and belonging within post-secondary institutions in Atlantic Canada is warranted.

Proposed Study

Leisure plays a key role in facilitating the development of one's identity and feelings of belonging, as engaging in leisure through different domains in one's life such as in community (Kelly & Godbey, 1992; Liu & Fu, 2019) can provide people with opportunities to further develop their sense of identity and feelings of belonging (Blackshaw, 2010; Spracklen et al., 2015). Thus, immigrant students' experiences of leisure can serve as a means for developing or enhancing their identity and feelings of belonging within a new community. This qualitative transformative study aims to explore leisure's role in cultivating a sense of identity, community, and belonging as experienced by immigrants attending post-secondary institutions in Halifax, Nova Scotia. Merleau-Ponty's principles of embodiment guide this study to understand lived and embodied experiences (Alcoff, 2006, Chapter 7; van Manen, 2014). A transformative paradigm is employed to actively engage participants through a collaborative and creative participatory data collection method, collage-making (Vacchelli, 2018), to amplify participants' voices, raise concerns, and, hopefully, enrich their lives and well-being (Creswell & Poth, 2018). Focus groups will subsequently be conducted to more deeply explore the memories, thoughts, and feelings elicited in the process and product of collage-making, specifically their experiences of leisure, identity, and belonging (Creswell & Poth, 2018; Vacchelli, 2018). Recordings from focus groups will then be transcribed and analyzed in conjunction with the collages.

Significance

Study findings can contribute to the literature about whether leisure experiences during post-secondary studies contribute to identity and feelings of belonging, and these can consequently assist faculty and university board members and community service providers in more deeply understanding immigrants' broader experiences of health and well-being. New knowledge from this study can also deepen our understanding of how leisure might contribute to immigrant students' resettlement experiences. Finally, new knowledge from this study can enhance the development of appropriate programs or services to support immigrant students' learning experiences and their overall health and well-being.

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HPJ HEALTHY POPULATIONS JOURNAL

Poem

To Heal in Place

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https://doi.org/10.15273/hpj.v1i1.10662

Abstract

This poem is a creative non-fiction on the emotional and personable aspects of high health-resource use in primary healthcare, which is typically called high-cost use. This work displays that there is a critical aspect of a patient lens missing from this academic discourse, especially given the context of rural inequalities of health and deeper ties to Social and Structural Determinants of Health. In this poem, I reflect on the connections with various community leaders and patients I encountered during my fieldwork in the Renfrew County of Ontario, Canada. Rural and remote population health must be understood from a sociocultural and intersectional framework given the different historical and contemporary backgrounds of these communities in Canada.

Author Biography

Lindsay J. Dorder (she/they) is an Afro-Indigenous woman from Suriname, the Dutch Caribbean. Their life honors the Arawak, Carib, and Afro-Caribbean ancestors of her heritage. She has a disability that causes her to stutter, and, from her lived experience, she advocates for the destigmatizing of mental illness in Caribbean youth. She spends most of her days on unceded Algonquin Territory, specifically, Odàwàg (Ottawa), where she is continually supporting grassroots organizations. Lindsay's current Master's of Health Sciences research applies critical spatial, social, and structural understandings to the patient journey in primary healthcare of rural and remote Canada. They aspire to continue health equity initiatives with Surinamese communities to cultivate knowledge translation, and the preservation of her tribal ancestry.

To Heal in Place

A pair of running shoes,
With white shoelaces
Two bows,
One knot

I thought, “There’s no snow /
Sneakers are fine.”

By the week’s end,
Thick flurries and the scent of firewood
Cemented a bitter cold

My housing host laughed,
“Please use my old boots.”
She said, “I think you’ll need them…”

She was right

Swift snowfall,
A sudden delay
But we drove on
Through that blizzard,
Where there are few streetlights
Very few.

I then remembered someone.

We met while travelling north,
A quiet, native woman, who needed treatment
In another city
Hours away from her birth home.

Her husband,
The Caregiver
Shared her story,

You see, the city hospital has become home.
She no longer lived where the roads bend with the lakes,

Where the streetlights are few.

Instead, spends her time away,
To heal

In the next days of my journey
I met others like her,
People tackling mazes of care and healing

And between the rhythm of our words
A Fear sinks into our small space.
They confess, “When will it happen /
When will I be too sick?”

Some knew it would happen
They would have to move,
Far away
From family, from friends.
Others would decide to stay.

They ask themselves,
“Will I be back in the hospital /

Will I have to heal away?”

And it happens
It happens so suddenly

In all these lives
The tangles of care and healing
Bring a Fear
Of what might be

And where the roads bend with the lakes,

Where the streetlights are few,

This Fear waits
In the places where nature cannot fill.

White shoelaces,
Borrowed snow boots

When will Healing take them from their homes?