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## Cover Artwork

## **Moosehide Moccasins**

Cassandra M. Bruhm Mount Saint Vincent University DOI: https://doi.org/10.15273/hpj.v1i2.11194

#### **About the Artist**



Cassandra M. Bruhm is an undergraduate student entering her 3<sup>rd</sup> year at Mount Saint Vincent University completing a Bachelor of Arts in Child and Youth Studies. Cassandra is from the South Shore of Nova Scotia where she lives with her parents, 2 sisters and 3 cats. She was trying to find more ways to get involved on campus when she came across The Indigenous Mentorship Network during her first year of university and has loved every moment of it. Cassandra started making moccasins just over a year ago in March of 2020 when the pandemic first started. She also recently started to learn how to bead by taking the Moccasin making course with the Indigenous Mentorship Network.

#### **About the Atlantic Indigenous Mentorship Network**

The Atlantic Indigenous Mentorship Network (Atlantic-IMN) is a regional network that offers mentorship, learning opportunities, and financial support to Indigenous students and early career researchers pursuing Indigenous health research and health professional programs. It is a collaboration among universities, communities and community-based organizations, and Indigenous governments across Nova Scotia, Prince Edward Island, New Brunswick, and Newfoundland and Labrador. Our goal is to support Indigenous-led health research in the Atlantic region.





Atlantic Indigenous Mentorship Network



@Atlantic\_IMN



#### Welcome from the Co-Editors-in-Chief

We are so pleased to welcome readers to the second issue of the *Healthy Populations Journal* (HPJ). HPJ is a student-run open-access peer-reviewed journal from the Healthy Populations Institute at Dalhousie University. Our focus is to highlight student-led population health research and support new authors in the academic publishing process. Following the publication of our inaugural issue in the spring of 2021, we received positive feedback from readers, reviewers, and researchers about the breadth and timeliness of published articles. We also received and continue to receive manuscript submissions from students locally, nationally, and internationally demonstrating a need for student-led and student-focused peer-reviewed journals that encourage diverse, creative, and intersectional forms of knowledge expression.

In this issue we are spotlighting student artwork from the Atlantic Indigenous Mentorship Network. Our cover features handmade moccasins by undergraduate student Cassandra Bruhm (Mount Saint Vincent University). There is a series of original sealskin flowers from Angelina Heer (University of New Brunswick) and Lauren Young (Dalhousie University). This issue also includes an original story by PhD student Kevin Mercurio. As a new feature in the second issue of the HPJ, we are now publishing infographics. Infographics are a short, summary of a research paper that capitalizes on visual representations of research purpose, impacts and outcomes to both increase interest in published research and increase its accessibility.

Articles in this issue cover timely, interesting, and important topics such as potential mental health benefits of smartphones in a leisure context (Ausman), learning needs and gaps in curriculum related to Indigenous health issues as perceived by first- and second-year medical students (Ley et al.), how environmental racism plays out for residents in Inuit Nunangat and Truro, Nova Scotia (Torrealba), how interprofessional collaboration can support the needs of children with complex needs while in healthcare (Lamb et al.) and what the experiences of using a patient navigation centre is like for caregivers of children with complex needs over a prolonged period (Knight et al.). Further, this issue features a review on caregivers' mental health related to the burden of caring for youth with conduct disorder (Doucet et al.), discussions about the reality of physician burnout in Canada (Manchanda), understanding university students' attitudes on verbal sexual consent (Matchett et al.), and research protocols for conducting a bibliometric analysis of anxiety and depression across the perinatal period (Dol et al.) and for conducting a scoping review on community-embedded mental health promotion programs (Heyland et al.).

HPJ would not be possible without support from the Healthy Populations Institute and the guidance from the HPJ Editorial Board Members. This is the last issue for managing editor and co-founder, Sara Brushett, without whom the creation of HPJ would not be possible. On behalf of the board, I extend a most heartfelt thank you to Sara for all her work on HPJ. This is also the last issue for Co-EiC Dr. Justine Dol, PhD. On behalf of the board, I would like to extend my gratitude to Justine for her guidance and leadership at HPJ.

We truly hope you enjoy reading volume 1, issue 2.

Christie Stilwell PhD in Health Student, Dalhousie University

Co-Editor-in-Chief, HPJ

Stephanie Zubriski PhD in Health Student,

Dalhousie University
Co-Editor-in-Chief (incoming), HPJ

Dr. Justine Dol, PhD St. Michael's Hospital

Co-Editor-in-Chief (out-going), HPJ



#### Welcome from the Managing Editors

I am proud to say that I am a co-creator and Managing Editor of the Healthy Population Journal. Looking back at the creation of the Competency Framework that was published in 2019, at that time I never thought that it would grow into this journal. Christie Stilwell and I had no idea if it was even possible to create our own journal, but here we are publishing our second issue. It is surreal to say the least. When we embarked on this journey, I was in the process of completing my master's thesis and knew that I had to plan for the day I left my role as both a student and the Managing Editor behind. What I did not expect was how hard leaving the journal would be. I am grateful for the Healthy Populations Institute for believing in this journal and supporting us at every step. I am thankful for Christie for co-creating the HPJ with me, and for all the work she continues to do. I am so thankful for every person who has volunteered their time to be on the Board. Finally, I am thankful for all of the authors and reviewers, for without you this journal would not have a purpose.

I am happy to hand over the role of Managing Editor to Julia Kontak, whom I know will do great work with the HPJ. Julia Kontak is a current PhD Student who has an extensive background in health promotion research and knowledge translation. It is only through knowing what great hands the journal is in that makes leaving the journal just a little easer.

On behalf of Julia and I, we hope you enjoy our Fall publication.

Sara Brushett

Managing Editor (outgoing), HPJ

Iulia Kontak

Julia Kontak

PhD in Health Student, Dalhousie University

Managing Editor (incoming) HPJ



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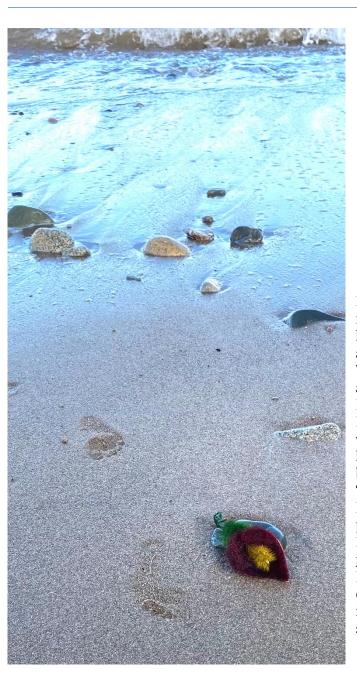


## Artwork

# Sealskin Flower by the Water

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<sup>1</sup>University of New Brunswick

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**About the Artist** 



My name is Angelina Heer and I am a member of Sucker Creek First Nation. I am living and working as a guest on the unceded and unsurrendered traditional lands of the Wolastogiyik and Mi'kmag People. I am also a graduate student in the MEd Counselling Program at the University of New Brunswick. My thesis is focused towards a wholistic perspective on the journey of healing for Indigenous men reintegrating back into community after incarceration. Atlantic Indigenous Mentorship Network (IMN) has become an important part of my journey as graduate student. The IMN provides a safe space to navigate the journey of Indigenous research in academia. I made this seal skin broach in a workshop offered by IMN. Working on my thesis has inspired me to reconnect with my creative side which got lost in the busyness of life.



## Artwork

## **Sealskin Flowers in the Forest**

Lauren Young<sup>1</sup>
<sup>1</sup>Dalhousie University

DOI: https://doi.org/10.15273/hpj.v1i2.11196



#### **About the Artist**



I am a second-year undergraduate student at Dalhousie University, and I am doing a Bachelor of Medical Sciences. I am a Mi'kmaq woman and I became a member of the Atlantic-IMN in my first year of university. They have given me opportunities to become more connected to my culture which has included creating these seal skin brooches as well as making my first pair of moccasins. I have always been an artistic person and have enjoyed visual arts using mediums such as paint, chalk, pencils, charcoal, and ink; performing arts in music playing piano, guitar, tenor

saxophone, and baritone saxophone. Having the opportunity to work on making brooches and moccasins has enabled me to explore a new form of art that made me feel more connected to natural elements within our world that are provided to us. The IMN gives a chance to step away from academics and connect with a community of people who share similar values and culture but varied life experiences. Despite COVID-19, they still offered an opportunity to connect virtually, and share knowledge and learnings. It is a great group and I look forward to future events as well as the chance to meet other members in person!



## Commentary

# Smartphones Aren't Completely Evil: Why Smartphones Should Be Explored as a Form of Leisure Coping

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#### **Abstract**

While many post-secondary students experience mental health challenges in regular circumstances, the additional challenges posed by the COVID-19 pandemic intensify the need for mental health solutions. Leisure has previously been identified as a positive coping strategy among students as it leads to improved health and well-being. As many students' own smartphones, technology that can be used to access and experience different types of leisure, this suggests the possibility of using smartphones as a form of leisure coping. However, as smartphones are often considered to be detrimental to health, exploring the potential mental health benefits they could provide students has scarcely been explored. This approach to examining the possible positive impacts of smartphones on student mental health is guiding upcoming research in leisure studies at Dalhousie University.



### Smartphones Aren't Completely Evil: Why Smartphones Should Be Explored as a Form of Leisure Coping

Post-secondary students are no strangers to mental health challenges, with 68.9% reporting overwhelming anxiety and 60.9% reporting more than average or tremendous stress in the last 12 months (American College Health Association, 2019). Coping strategies among these students can vary, although some are considered more adaptive when they lead to higher stress tolerance and increased resilience, such as participation in leisure (Denovan & Macaskill, 2017). There are many definitions of leisure, and definitions have changed over time (Veal, 2019), but the term as used here refers to enjoyable activities participated in during one's free time (Kleiber, 1999). Leisure as a form of coping among students has been connected to improved health and well-being (Denovan & Macaskill, 2017) and therefore highlights the importance of leisure participation among this population. In Canada, 97.9% of internet users aged 15 to 24 years old own a smartphone (Statistics Canada, 2021). As smartphones have a variety of leisure purposes (e.g., streaming services, games, internet access, social media) alongside other uses, this presents an opportunity to explore smartphones as a tool for accessing leisure, and therefore, potentially as a tool used for leisure coping.

Although both the smartphone-leisure and leisure-health connections have been largely accepted, gap remains understanding the connection between smartphone-based leisure and its possible health benefits. One experimental study, examining the use of smartphones for coping, found that smartphones can act as a security blanket in times of stress by increasing an individual's resilience to stressful events (Panova & Lleras, 2016). As smartphones can be used for coping (Panova & Lleras, 2016) and also for leisure due to their many applications, it follows that students' use of smartphones may be considered leisure coping. In turn, if leisure coping leads to improved health, well-being, and

resiliency (Denovan & Macaskill, 2017), then it is possible the use of smartphones for leisure coping could provide some of these beneficial outcomes as well.

A study found that over 60% of Canadian adults increased their screen time in the early stages of the COVID-19 pandemic (Zajacova et al., 2020). In addition, the pandemic introduced a variety of other mental health challenges for students (Statistics Canada, 2020). These outcomes present additional reasons for researchers to examine the role smartphones can play in coping. Upcoming research currently underway at Dalhousie University aims to not only discover how smartphones are being used as a form of leisure coping among students, but how this person-technology relationship may have been impacted by the COVID-19 pandemic. Participants completed an online anonymous survey that included quantitative measures such as the Leisure Coping Beliefs Scale Short-Form and Leisure Coping Strategies Scale Short-Form, which were both modified to focus on smartphone-related leisure; the Immediate Adaptational Outcomes scale, measuring coping effectiveness; the Perceived Stress Scale; the Generalized Anxiety Disorder 7-item scale; and the Brief Resilience Scale. Qualitative questions were included to help contextualize the above measures. As students have a high prevalence of both smartphone ownership and mental health challenges, this population is best suited for research exploring the role of smartphones in leisure coping. This study will inform future research in coping, leisure, and smartphone literature to help better understand and contextualize post-secondary student use of smartphones within the context of health.

#### Acknowledgements

I thank Dr. Susan Hutchinson, Kimberley Woodford, Dr. Niki Kiepek, and Dr. Sara Kirk for their expertise and assistance in this research and its proposal.



#### References

- American College Health Association. (2019).

  American College Health Association—
  National College Health Assessment II:
  Canadian consortium executive
  summary, spring 2019.
  https://www.cacuss.ca/files/Research/
  NCHA- II%20SPRING%202019%
  20CANADIAN%20REFERENCE%20GRO
  UP%20EXECUTIVE%20SUMMARY.pdf
- Denovan, A., & Macaskill, A. (2017). Stress, resilience and leisure coping among university students: Applying the broaden-and-build theory. *Leisure Studies*, *36*(6), 852–865. https://doi.org/10.1080/02614367.20 16.1240220
- Kleiber, D. A. (1999). Leisure experience and human development: A dialectical interpretation. Basic Books.
- Panova, T., & Lleras, A. (2016). Avoidance or boredom: Negative mental health outcomes associated with use of information and communication technologies depend on users' motivations. *Computers in Human Behavior*, *58*, 249–258. https://doi.org/10.1016/j.chb.2015.12.062
- Statistics Canada. (2020, May 12). Impacts of the COVID-19 pandemic on postsecondary students.

  https://www150.statcan.gc.ca/n1/en/daily-quotidien/200512/dq200512a-eng.pdf?st=1HnsYrS-
- Statistics Canada. (2021, June 22). *Table 22-10-0115-01: Smartphone use and smartphone habits by gender and age group.* https://doi.org/10.25318/2210011501-eng
- Veal, A. J. (2019). Joffre Dumazedier and the definition of leisure. Loisir et Société / Society and Leisure, 42(2), 187–200. https://doi.org/10.1080/07053436.20 19.1625533

Zajacova, A., Jehn, A., Stackhouse, M., Denice, P., & Ramos, H. (2020). Changes in health behaviours during early COVID-19 and socio-demographic disparities: A cross-sectional analysis. *Canadian Journal of Public Health, 111*(6), 953–962. https://doi.org/10.17269/s41997-020-00434-y



## Research Article

# From Inuit Nunangat to the Marsh: How Climate Change and Environmental Racism Affect Population Health

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#### **Abstract**

It is widely accepted in the scientific community and beyond that climate change presents an immediate and severe threat to human health and well-being. However, the consequences of climate change are not experienced equally across all populations. Black and Indigenous communities are disproportionately exposed to harmful, hazardous, and often toxic activities and pollutants—a form of racial violence known as environmental racism. To understand how environmental racism, exacerbated by climate change, affects population health, I will explore two examples of environmental racism in Inuit Nunangat in the Arctic and in Truro, Nova Scotia. Finally, I will discuss social capital and power in the context of environmental racism—incorporating an eco-social perspective when addressing environmental racism—and the ways in which population health researchers can help narrow the health gap caused by environmental racism and climate change.



# From Inuit Nunangat to the Marsh: How Climate Change and Environmental Racism Affect Population Health

I, the author, am a settler-student attending Dalhousie University, which is located in Kjipuktuk (Halifax), in Mi'kma'ki—the ancestral and unceded territory of the Mi'kmag nation. I am White, and I wish to make clear my position as an individual who has personally benefitted from White privilege. The purpose of this paper is to learn from the expertise and systemically experiences of marginalized individuals and groups who are cited throughout this paper, and to further understand my role and the roles of the institutions with which I am affiliated—in upholding oppressive systems.

#### Introduction

The consequences of climate change are not experienced equally across all populations. While wealthy individuals and corporations continue to profit from the exploitation of natural resources, marginalized communities suffer the brunt of the impact. Concerns of rampant environmental racism in Canada were raised by the Canadian Human Rights Commission in the 2020 report of the UN Special Rapporteur on toxics and human rights (United Nations Human Rights Council, 2020). There is a growing body of work on environmental racism in Canada, and the literature on climate changerelated health outcomes is extensive. The current paper aims to bring these two fields of study together, with Solar and Irwin's (2010) social determinants of health framework in mind. In this paper I will explore how environmental racism and the resulting population health inequities are made worse by climate change. I will describe two examples of environmental racism: rising sea levels in Inuit Nunangat in the Arctic, and flooding in three communities in Truro, Nova Scotia. Finally, I will discuss social capital (which refers to the networks and relationships forged between individuals within a population) and power in the context of environmental racism, and the ways in which population health researchers

can help narrow the health gap caused by environmental racism and climate change.

#### **Climate Change and Environmental Racism**

It is widely accepted in the scientific community and beyond that climate change presents an immediate and severe threat to human health and well-being. Increasing anthropogenic greenhouse gas emissions (greenhouse gas emissions caused by human activity) cause rising global temperatures and other climatic changes, resulting in adverse health effects worldwide (McMichael et al., 2006). For example, the European heat wave of 2003 led to approximately 70,000 deaths, with the risk of heat-related mortality in Paris increasing by 70% due to anthropogenic climate change (Mitchell et al., 2016). An epidemiologic review of studies from cities across North and South America, Europe, Australia and Asia found that increasing ambient temperatures were associated with heightened risk of mortality, and that Black people, women, and people in lower socioeconomic positions particularly vulnerable (Basu, 2009). In Lhasa, China, climate change facilitated establishment of Culex pipiens complex mosquitoes, which are carriers of a number of diseases including West Nile (Liu et al., 2013). The examples are endless, and the consequences are dire.

Broadly, climate change affects human health through three basic pathways: (a) direct health implications associated with extreme weather events, including flooding, droughts, and storms; (b) health effects mediated via natural systems, including air pollution, and vector-, food- and water-borne diseases; and (c) health effects mediated via human systems, including food insecurity, displacement, mental health challenges, and violence and conflict (McMichael et al., 2006; Smith et al., 2014). In this paper, I will mainly explore the third pathway, linking climate change to social, economic, and demographic disturbances, and their subsequent effects on health.

Canadian environmental policies and legislature often negatively target racialized populations, particularly Black, Indigenous, and



People of Colour (BIPOC). Black and Indigenous communities are disproportionately exposed to harmful, hazardous, and often toxic activities and pollutants, and this is a form of racial violence known as environmental racism (Waldron, 2016). Environmental precipitates a multitude of health risks, and these risks are exacerbated by climate change. Environmental racism has become more prominent in discourse surrounding movement for climate and environmental justice in recent years; however, the issue is often pushed to the side or conflated with other environmental issues. Without input from affected communities and an emphasis on racial justice, environmental activists fail to address the root of environmental racism.

The term environmental racism was coined by American researchers in the 1980s, and much of the existing literature comes from the United States (Jacobs, 2010; Northridge & Shepard, 1997). There is a lack of literature on the mechanisms by which climate change and environmental racism intersect, and on exactly how environmental racism is intensified by worsening climate change. One example that demonstrates this intersection is the way Black Americans in New Orleans experienced Hurricane Katrina in August of 2005.

Following the hurricane, predominantly Black communities and livelihoods were disproportionately and catastrophically damaged. The contemporary vestige of colonial plantations in New Orleans, or the "White Teapot," is a collection of predominantly White neighbourhoods that are situated at high elevations, far from riverside and backswamp nuisances (Morse, 2008). Conversely, predominately Black neighbourhoods in New Orleans were built at low elevations, at high risk of flooding from swamps and rivers and isolated due to the location of federal housing and poor access to transportation (Morse, 2008). These factors made Black communities more vulnerable to hurricane-related flooding than White communities. Not only were Black communities disproportionately damaged by Hurricane Katrina, but they also dealt with the disparities for far longer than White people who

were affected by the hurricane. On August 31st, what is considered the final day of the weather event, 67% of Black residences in New Orleans were flooded, compared to 51% of White residences. Over one week later, on September 8th, 60% of Black residences remained flooded compared to 24% of White residences (Morse, 2008). From this example it is clear how environmental racism and the resulting disparities in health, safety and security—in this case, the geographic location and lack of infrastructure for Black communities—were exacerbated by an extreme weather event, which is likely to occur more frequently and can be more severe due to climate change.

An understanding of the "complex web of inequalities" (Waldron, 2018, p. 92) is necessary to understand how environmental affects Black and **Indigenous** communities. Structural determinants of health approaches emphasize the need for a holistic inequalities. of health including view socioeconomic position, food insecurity, housing, social class, education, biological factors, gender, and so forth (Solar & Irwin, Therefore, 2010). when assessing environmental racism and climate change, it is crucial to go beyond strictly clinical assessments of health or quantitative measures of physical damage following a storm. Rather, we must tackle overlapping and intersecting stressors that increase vulnerability to environmental dangers in systematically marginalized and racialized groups (Waldron, 2018).

#### **Inuit Nunangat**

Coastal regions are disproportionately impacted by rising sea levels. Today, climate change continues to affect Inuit populations living on coastal Inuit Nunangat, which includes Nunatsiavut, Nunavik, Nunavut and the Inuvialuit Settlement Region. Nunangat means "homeland" in Inuktitut, and refers to the land, water, and ice in the aforementioned four (Oceans North, n.d.). regions Due environmental racism, colonial violence. intergenerational trauma and forced cultural assimilation, there are vast disparities in health between Inuit and non-Inuit in Canada. Culture



is a key component in a healthy community, and the loss of a traditional culture and language can be detrimental to social capital, knowledge translation, and ultimately, health (Greenwood et al., 2015). Inuit living in Inuit Nunangat have an average life expectancy of 67.3 years, compared to the national Canadian average of 79.5 years (Harper et al., 2012). The rates of suicide and self-inflicted injury among Inuit are almost 10 times higher than the national average, and all-cause mortality (standardized by age) is almost 40 times higher among Inuit than the national average (Harper et al., 2012). With population health inequities already a major cause for concern among Inuit, the severe and complex effects of climate change further negatively influence these disparities. In Rigolet, Nunatsiavut, 88% of surveyed community members reported that climatic environmental changes were concerning, with 76% reporting that climate change had resulted in changes to their health (Harper et al., 2012).

The health-related impacts of climate change manifest in Inuit Nunangat in a number of ways, including decreased personal safety, increased food and water insecurity, and poor mental health (Ford et al., 2014). Climate change leads to rapidly changing weather and melting sea ice, making land, sea and ice conditions difficult to predict and thus increasing one's risk of injury or death while travelling and hunting in Inuit Nunangat (Ford et al., 2014). Moreover, accessing health care and emergency medicine can be extremely difficult in Inuit Nunangat, further increasing health and fatality risks associated with climate change. With the changing environment, Inuit livelihoods are also at risk, as hunting, fishing, culture, diet and wellbeing are detrimentally impacted (Ford et al. 2014; Harper et al., 2012).

Food insecurity is another major concern among Inuit: there is a lack of access, availability, and quality of food in Inuit Nunangat. Hunting, fishing, and gathering are important aspects of Inuit culture, and traditional foods, including seal, beluga whale, caribou, Arctic char and wild berries, are staples of contemporary Inuit diets (Ford, 2009). Traditional foods and traditional modes of food

preparation are culturally and economically significant, nutritious, and sustainable. They are important mechanisms of social capital and community building, with food sharing within and between households guided by kinship rules (Ford, 2009). Over the past few decades, store-bought foods have become a more popular part of the Inuit diet, which poses a number of challenges in Inuit Nunangat. Most of Inuit Nunangat is only accessible by air, winter roads, and boat (only in the summer), making it extremely challenging to deliver non-perishable food items and fresh produce (Ford, 2009). All of these modes of travel are weather dependent, and are thus vulnerable to climate change and unpredictable weather. Similarly, traditional food acquisition is vulnerable to climate change as hunting becomes more challenging due to changes in snowfall, melting sea ice and availability of certain animals, leading to new or worsening problems of food insecurity (Ford, 2009; Ford et al., 2014). Food insecurity is associated with a number of negative health outcomes, including vitamin and mineral deficiencies, poor self-rated health, dental problems, and mental illness (Gundersen & Ziliak, 2015).

Moreover, respiratory disease-related mortality is approximately five times higher among Inuit living in Inuit Nunangat compared the Canadian average, and rates of tuberculosis are over 290 times higher among Inuit, compared to non-Indigenous Canadians (Harper et al., 2012; Patterson et al., 2018). The root causes of these disproportionate rates of respiratory disease lie in the social and structural determinants of health, particularly in insufficient housing. Over half (52%) of Inuit live in social housing, which often sees upwards of 20 people sharing a four-bedroom house (Patterson et al., 2018). Most dwellings are overcrowded, in dire need of repairs, infested with mould, and "below housing standards" (Bell, 2020, para 12). The housing crisis in Inuit Nunangat and lack of response from the federal government is an example of systemic racism. As stated by Mumilaaq Qaqqaq, formerly Nunavut's New Democratic Party MP, "the whole system keeps Inuit oppressed" (Bell, 2020, para 18).



Climatic and environmental changes in ambient temperature are predicted to worsen the effects of respiratory diseases, including tuberculosis, in part due to forced displacement and inadequate housing (Smith et al., 2014). These inequities intersect to situate Inuit in an extremely vulnerable position in relation to the negative effects of climate change on respiratory health.

Despite these gaps in population health and well-being, the Canadian government has invested a limited budget in climate changerelated health research and policy changes, with inadequate resources allocated to Indigenous communities in the North (Ford et al., 2014). According to Ford et al. (2014), "this investment represents a small fraction of other federal expenditures and is insufficient for a problem as complex and potentially damaging to human and environmental health as climate change" (p. e10). The lack of support for Inuit, who are being disproportionately affected by climate change and ongoing colonial violence, is an example of environmental racism on the part of the Canadian government. Local action is ongoing: traditional knowledge of hunting practices, food sharing networks, land-based knowledge, and the incorporation of traditions and cultures into health practices are all ways in which Inuit are resilient, despite resistance and lack of support from the government (Ford et al., 2014).

Notably, in discussing anti-Indigenous environmental racism, it is critical to recognize the significance of the land to Indigenous peoples:

To indigenous peoples, land is not just physical and biological environment. The land is the ash of their ancestors who fought to keep the land from becoming destroyed by others: the ancestors on whose shoulders we stand in this generation, whose land we must preserve for the next seven generations. (Colomeda & Wenzel, 2000, p. 249)

For Inuit, strong relationships with the environment and land are critical in maintaining culture, traditions and well-being. In a study that interviewed Community Health Representatives

(CHRs) from First Nation and Inuit communities in Canada, environmental/cultural connections were identified as one of six primary determinants of health (Richmond & Ross, 2009). Debbie, a CHR, gives the following explanation:

In my community, we are more northern and we have traditional foods that we depend on. We travel on the land, we socialize more together, and we know each other, and that is good. We always go on word of mouth, if somebody is going through this or that, and this means everybody gets involved. We are lucky to have that. (Richmond & Ross, 2009, p. 407)

Inuit Qaujimajatuqangit, which translates to "that which Inuit have always known to be true" (Tagalik, 2009–2010, p. 1), refers to knowledge, systems of beliefs, and values in Inuit culture it is a living, dynamic episteme. As climate change drastically impacts the land in Inuit Nunangat, systems of traditional knowledge translation like Inuit Oaujimajatuqangit—a kev cultural determinant of health—are at risk. Community members, Elders, and hunters have expressed concerns with the unpredictable climate and how it will impact transportation and traditional routes of travel. Sytukie Joami, a community member from Igaluit, describes the changes they have witnessed: "It is getting more unpredictable as to what will happen; because the signs are misleading the Inuit who are used to weather that follows these signs" (Nunavut Climate Change Centre, n.d.). Environmental dispossession and reduced access to traditional territories are associated with decreased access to social capital and cultural and intermediary determinants of health, thus negatively impacting health outcomes (Ford et al., 2014; Greenwood et al., 2015). Furthermore, when examining determinants of Indigenous peoples' health in Canada, colonialism is viewed as the single most important determinant of health for many Indigenous peoples (Waldron, 2018). Greenwood et al. (2015) argue that current frameworks of social determinants of health tend to exclude colonialism, spirituality,



relationship to the land, knowledge systems and other determinants of health that are not necessarily *social*. Incorporating colonialism into current frameworks will be more complicated than simply adding colonial violence to a list of determinants. It will require an intersectional, cross-cutting understanding of how colonialism interacts with other determinants of health, including gender, ethnicity, social capital, societal values, and culture.

#### The Marsh, the Island, and the Hill

Precipitation, snow cover, soil moisture content, sea levels, glacial lake conditions, and vegetation are all factors that both affect flood characteristics and are affected by climate change (Seneviratne et al., 2012). Over the past few decades, flood frequency has increased across the world, as has the risk of extreme flooding. These changes can be partially changes attributed to in the climate (Seneviratne et al., 2012). Extreme flooding can destrov homes, hospitals, crops, and transportation, all the while increasing rates of infectious diseases. including cholera. vector-borne respiratory infections, and diseases (Ohl & Tapsell, 2000). The literal and figurative rebuilding that must occur after floods causes lasting emotional trauma and psychological stress (Ohl & Tapsell, 2000).

Flooding has been a major issue for the Marsh, the Island and the Hill—three historically African Nova Scotian neighbourhoods in Truro, Nova Scotia. Each neighbourhood is named after the land that encompasses it, as described by a community member of the Island and referenced by Millman (2019):

[...] when the Black people came to Truro, they weren't allowed to live in town, they put them on the Marsh, where it was marshy, way over the Hill, where it was hilly and trees, and they put us up here because apparently when it used to rain, or whatever, the water used to surround it. That's how it got called the Island. (p. 42)

Due to rising river levels and increased rainfall, fluvial and pluvial floods are becoming more prevalent in these communities, bursting dikes and detrimentally impacting livelihoods (Corfu, 2016; Segal, 2014; Tutton, 2012). Residents of the communities have expressed concerns about the impacts of the floods, but have had little to no support from government bodies at the municipal, provincial, and federal levels. Anthropogenic climate change results in unpredictable and potentially more dangerous instances of flooding and other extreme weather events, and there are therefore growing concerns of how flooding will continue to impact African Nova Scotian communities in Truro.

For coastal regions like Nova Scotia, flooding will become more frequent with climate change. The Nova Scotia Department of Environment has expressed concern about the increased flooding, but the emphasis seems to be on protecting infrastructure rather than communities. According to a representative of the Nova Scotia Department of Environment, the flooding can be better managed and there is a lot of progress to be made "especially in areas where we have critical infrastructure that we need to protect" (Pace, 2015, para 11). Meanwhile, the general conclusion from the 2015 Atlantic Flood Management Conference in Truro was that "people in the region need to adapt" (Pace, 2015, para 1). Many community members from the Marsh were repeatedly displaced as a result of flooding and were forced to move into rental housing, as they could not afford to repair their flood-damaged homes (Waldron, 2016). Inexplicably, many were not eligible for flood insurance, despite how frequently floods occur in the area (Waldron, 2018). The health, safety, and well-being of Black community members has been directly and disproportionately impacted by the floods, but the emphasis on rebuilding and protection remains focused toward infrastructure and away from communities.

Furthermore, one of the major concerns among residents of the Marsh, the Island, and the Hill is the lack of African Nova Scotian representation and involvement in policymaking in Truro (Waldron, 2018). Residents



receive little support or response from the government, compared to their well-represented White counterparts, as described by an African Nova Scotian community member from Truro and referenced by Waldron (2016):

And as white people move into the communities, whether it's the Island, the Hill or the Marsh, they start to do things to enhance ... perception to enhance the area. Whereas, as long as it was predominantly a Black area, they just left it as it was and figured, you know, we don't do anything to enhance the area or to improve the area. But, as soon as one white person moves into the area, then all of a sudden, "okay, let's see what we can do." (p. 14)

A lack of action and collaboration from the government amplifies racial hierarchies and health inequities in the area, clearly illustrating how social policies are failing African Nova Scotians. The difference in the response between when a White community is vulnerable to flooding and when a Black community is vulnerable shows how "climate change is set to exacerbate existing disregard for Black life, in part through the very universalism embedded in the claim that 'all lives matter'" (Sealey-Huggins, 2018, p. 101).

#### **Social Capital and Power**

It is important to examine the concept of social capital in the context of environmental racism. As described by Solar and Irwin (2010), social capital acts as a link between structural (socioeconomic position, social class, racism, etc.) and intermediary (behaviours, biological factors, psychosocial factors, etc.) determinants of health. Putnam (2000, p. 67) defines social capital as the "features of social organization, such as networks, norms and social trust, that facilitate coordination and cooperation for mutual benefit." In the context of environmental racism and climate change, strong social capital among members of a community is health protective, in the sense that a community network and mutual respect are beneficial to one's well-being. Furthermore, co-operative

relationships among groups in different positions along a gradient of power (referred to as linking social capital) is an important aspect of health policy (Solar & Irwin, 2010). Collaborative efforts between community members and policy-makers are one mechanism through which environmental racism can be addressed.

Social capital, however. is controversial term. Muntaner (2004) argues that social capital is used by public and population health researchers as a comforting metaphor that implies that capitalism and social cohesion can somehow work together harmoniously. As Muntaner maintains, "capitalism creates competition and inequality, and thus tends to erode social integration" (p. 675). Climate change is fueled by capitalism and colonialism and imperialism. Capitalism shapes economic systems and policies, with profit and economic growth prioritized at the of environmental iustice population health (Sealey-Huggins, 2018). Therefore, in the context of environmental racism and climate change, perhaps social capital is not the best terminology to use. Instead, the term "social cohesion" and other similar terms are distinct from capitalism, and holistically sum up the important communitydriven pathways that protect health (Muntaner, 2004). Social cohesion emphasizes networks relationships among communities beginning at a societal level, whereas descriptions of social capital typically begin at the individual level.

Going beyond the discussion of social capital, and what I argue is more important in addressing environmental racism and climate change, is the redistribution of power. In the discourse of health determinants, the central role of power refers to the political contexts and social, public, and economic policies that engage both the agency of marginalized disadvantaged populations and the accountability of the state (Solar & Irwin, 2010). Theories of power in regard to health equity are grounded in theories of human rights, based heavily in the discipline's prevailing emphasis on the need for restoring power to oppressed



and marginalized populations. Empowerment and the equal distribution of power are central to the rights to health and to have control and autonomy over one's own health. Fundamentally, environmental racism is one mechanism through which racialized groups are stripped of their power and resources via systemic disempowerment, unjust distribution of power along White supremacist ideals, and violation of rights to health and health autonomy.

#### **Moving Forward**

When considering how to best address the connected issues of climate change and environmental racism, I want to recognize that much of the work is already underway. Community members *have been* advocating for themselves and their communities and continue to do so. What is missing is the support, funding, and collaboration from policy-makers. Waldron (2016) references an African Nova Scotian community member from Truro who described government inaction in regard to the flooding:

Every year I try to address the flood with government. And even to the Town representatives. And, it gets back with trying—'We're trying'. That's been going on for over 60 years. And, the big problem with that is we have no political clout. We have no political organizations in our community. But, if we had an organization speaking on behalf of the communities, that would have a lot more clout. (p. 22)

The disconnect between the needs of the community and environmental policy-making prohibits the improvement of health outcomes in racialized communities.

In reference to the environmental justice movement, Waldron (2018) writes: "Those agendas [of environmental activists] often seek to subsume environmental racism within the broader (and more comfortable) environmental justice lens, in which racism gets displaced from its rightful place at the centre" (p. 15). To echo Waldron, there is no environmental justice without racial justice, and environmental racism

should thus be viewed as a distinctive mechanism of injustice. Similarly, I argue that environmental racism should be viewed as a distinct determinant of health in the study of epidemiology and population health, especially as climate change continues to be a prominent and growing area of research and policy. More quantitative and qualitative community-led research is needed in order to adequately assess the intersection of environmental racism and climate change in Canada.

Theory matters when defining social epidemiology and analyzing epidemiological eco-social (Krieger, 2001). The perspective emphasizes the need to consider social, biological, historical and ecological factors as intersectional influences on health that cannot be considered in isolation (Krieger, 2001). Krieger proposes six multi-level pathways to explain the connections between racial discrimination, violence, and biological embodiments of poor health: (a) economic and social deprivation, (b) toxic substances and hazardous conditions, (c) socially inflicted trauma, (d) targeted marketing of commodities, (e) inadequate health care, and (f) resistance to racial oppression (Krieger, 2001). We can situate environmental racism within the first and second pathways. In the two examples that I described, racialized communities were deprived of economic and social resources (e.g., food, proper housing, traditional knowledge) and were subject to hazardous conditions (e.g., flooding, melting sea ice). Through these pathways, Krieger emphasizes that differences in biology and health outcomes are not a result of race, but a result of racism. It is racism that leads to disproportionate numbers of landfills in African Nova Scotian communities; racism that drives decades-long boil-water advisories on Indigenous reserves; and racism that triggers a quick government response to a disaster in a wealthy White community, but radio silence when that same disaster occurs in a systematically marginalized one.

Climate change negatively and disproportionately impacts population health among racialized groups due to environmental racism. To address the impacts of environmental



racism and climate change on population health, I believe there are two major actions that must take place. Firstly, there is the redistribution of power. Due to colonialism, socially-inflicted trauma, and socioeconomic inequities, Black and Indigenous communities have been disenfranchised and disempowered by colonial and White supremacist systems. Restoring power to communities is necessary in designing environmental interventions that account for important social and cultural dimensions. Secondly, policy-makers and government bodies must be held accountable for their role in perpetrating environmental racism, both through their action and inaction. As the environmental justice movement continues to grow, support and acknowledgement is needed from all levels. Irrefutably, "the climate crisis is a racist crisis" (#BlackLivesMatterUK, 2021), and it is the health of systematically racialized and marginalized populations that have suffered and will continue to suffer excessively if trends continue.

#### References

- Basu, R. (2009). High ambient temperature and mortality: A review of epidemiologic studies from 2001 to 2008. Environmental Health, 8, Article 40. https://doi.org/10.1186/1476-069x-8-40
- #BlackLivesMatterUK [@ukblm]. (2021, August 9). *The climate crisis is a racist crisis #ClimateEmergency* [Tweet]. Twitter. https://twitter.com/ukblm/status/142 4730260684345352?lang=en
- Bell, J. (2020, August 24). Nunavut housing crisis an example of systemic racism, MP says. *Nunatsiaq News.* https://nunatsiaq.com/stories/article/nunavut-housing-crisis-an-example-of-systemic-racism-mp-says/
- Colomeda, L. A., & Wenzel, E. R. (2000).

  Medicine keepers: Issues in Indigenous health. *Critical Public Health*, *10*(2), 243–256.

  https://doi.org/10.1080/713658247

- Corfu, N. (2016, February 16). Truro prepares for heavy rains and possible flooding. *CBC News*. https://www.cbc.ca/news/canada/nov a-scotia/storm-flooding-truro-mayor-1.3450930
- Ford, J. D. (2009). Vulnerability of Inuit food systems to food insecurity as a consequence of climate change: A case study from Igloolik, Nunavut. *Regional Environmental Change*, 9(2), 83–100. https://doi.org/10.1007/s10113-008-0060-x
- Ford, J. D., Willox, A. C., Chatwood, S., Furgal, C., Harper, S., Mauro, I., & Pearce, T. (2014). Adapting to the effects of climate change on Inuit health. *American Journal of Public Health*, 104(S3), e9–e17. https://doi.org/10.2105/ajph.2013.301724
- Greenwood, M., de Leeuw, S., Lindsay, N. M., & Reading, C. (Eds.) (2015). Determinants of Indigenous peoples' health in Canada: Beyond the social (1st ed.). Canadian Scholars' Press.
- Gundersen, C., & Ziliak, J. P. (2015). Food insecurity and health outcomes. *Health Affairs*, *34*(11), 1830–1839. https://doi.org/10.1377/hlthaff.2015.0 645
- Harper, S. L., Edge, V. L., Cunsolo Willox, A., & Rigolet Inuit Community Government. (2012). 'Changing climate, changing health, changing stories' profile: Using an EcoHealth approach to explore impacts of climate change on Inuit health. *EcoHealth*, 9(1), 89–101. https://doi.org/10.1007/s10393-012-0762-x
- Jacobs, B. (2010, May 20). Environmental racism on Indigenous lands and territories.
  Canadian Political Science Association.
  https://www.cpsa-acsp.ca/papers-2010/Jacobs.pdf
- Krieger, N. (2001). Theories for social epidemiology in the 21st century: An ecosocial perspective. *International Journal of Epidemiology*, *30*(4), 668–



- 677.
- https://doi.org/10.1093/ije/30.4.668
- Liu, Q., Liu, X., Cirendunzhu., Woodward, A.,
  Pengcuociren., Bai, L., Baimaciwang.,
  Sang, S., Dazhen., Wan, F., Zhou, L., Guo,
  Y., Wu, H., Li, G., Lu, L., Wang, J., Dawa.,
  Chu, C., & Xiraoruodeng. (2013).
  Mosquitoes established in Lhasa city,
  Tibet, China. *Parasites & Vectors*, 6,
  Article 224.
  https://doi.org/10.1186/1756-3305-6-
- McMichael, A. J., Woodruff, R. E., & Hales, S. (2006). Climate change and human health: Present and future risks. *The Lancet*, *367*(9513), 859–869. https://doi.org/10.1016/s0140-6736(06)68079-3
- Millman, P. (2019). African Nova Scotian youth experience on the Island, the Hill, and the Marsh: A study of Truro, Nova Scotia in the 1950s and 1960s (Publication No. 13901920) [Master's thesis, University of Lethbridge]. ProQuest Dissertations Publishing.
- Mitchell, D., Heaviside, C., Vardoulakis, S.,
  Huntingford, C., Masato, G., Guillod, B. P.,
  Frumhoff, P., Bowery, A., Wallom, D., &
  Allen, M. (2016). Attributing human
  mortality during extreme heat waves to
  anthropogenic climate
  change. *Environmental Research*Letters, 11(7), Article 074006.
  https://doi.org/10.1088/17489326/11/7/074006
- Morse, R. (2008). *Environmental justice through* the eye of Hurricane Katrina. Joint Center for Political and Economic Studies, Health Policy Institute.
- Muntaner, C. (2004). Commentary: Social capital, social class, and the slow progress of psychosocial epidemiology. *International Journal of Epidemiology,* 33(4), 674–680. https://doi.org/10.1093/ije/dyh200
- Northridge, M. E., & Shepard, P. M. (1997). Comment: Environmental racism and public health. *American Journal of Public Health, 87*(5), 730–732.

- https://dx.doi.org/10.2105%2Fajph.87. 5.730
- Nunavut Climate Change Centre. (n.d.). Voices from the land—Quotes by community: Iqaluit.

  https://www.climatechangenunavut.ca/en/knowledge/voices-land
- Oceans North. (n.d.). *Inuit Nunangat*. https://oceansnorth.org/en/where-we-work/inuit-nunangat/
- Ohl, C. A., & Tapsell, S. (2000, November 11). Flooding and human health. *The BMJ*, *321*, 1167–1168. https://doi.org/10.1136/bmj.321.7270. 1167
- Pace, N. (2015, March 5). Flooding problems won't recede in Atlantic Canada: Experts. *Global News*. https://globalnews.ca/news/1866192/flooding-problems-wont-recede-in-atlantic-canada-experts/
- Patterson, M., Flinn, S., & Barker, K. (2018).
  Addressing tuberculosis among Inuit in Canada. *Canada Communicable Disease Report, 44*(3–4), 82–85.
  https://doi.org/10.14745/ccdr.v44i34a 02
- Putnam, R. D. (2000). *Bowling alone: The collapse and revival of American community.* Simon & Schuster.
- Richmond, C. A. M., & Ross, N. A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health & Place*, *15*(2), 403–411. https://doi.org/10.1016/j.healthplace.2 008.07.004
- Sealey-Huggins, L. (2018). 'The climate crisis is a racist crisis': Structural racism, inequality and climate change. In A. Johnson, R. Joseph-Salisbury, & B. Kamunge (Eds.), The fire now: Antiracist scholarship in times of explicit racial violence (pp. 99–116). Zed Books.
- Segal, M. (2014, November 27). Truro's Park Street floods again following rain. *CBC News*. https://www.cbc.ca/news/canada/nov



a-scotia/truro-s-park-street-floodsagain-following-rain-1.2852673

Seneviratne, S. I., Nicholls, N., Easterling, D., Goodess, C. M., Kanae, S., Kossin, J., Luo, Y., Marengo, J., McInnes, K., Rahimi, M., Reichstein, M., Sorteberg, A., Vera, C., & Zhang, X. (2012). Changes in climate extremes and their impacts on the natural physical environment. In C. B. Field, V. Barros, T. F. Stocker, D. Qin, D. J. Dokken, K. L. Ebi, M. D. Mastrandrea, K. J. Mach, G.-K. Plattnew, S. K. Allen, M. Tignor, & P. M. Midgley (Eds.), Managing the risks of extreme events and disasters to advance climate change adaptation: Special report of the Intergovernmental Panel on Climate Change. (pp. 109–230). Cambridge University Press.

https://www.ipcc.ch/site/assets/uploa ds/2018/03/SREX-Chap3\_FINAL-1.pdf

Smith, K. R., Woodward, A., Campbell-Lendrum, D., Chadee, D. D., Honda, Y., Liu, Q., Olwoch, J. M., Revich, B., and Sauerborn, R. (2014). Human health: Impacts, adaptation, and co-benefits. In C. B. Field, V. R. Barros, D. J. Dokken, K. J. Mach, M. D. Mastrandrea, T. E. Bilir, M. Chatterjee, K. L. Ebi, Y. O. Estrada, R. C. Genova, B. Girma, E. S. Kissel, A. N. Levy, S. MacCracken, P. R. Mastrandrea, & L. L. White (Eds.), *Climate change 2014:* Impacts, adaptation, and vulnerability. Part A: Global and sectoral aspects. Contribution of Working Group II to the Fifth Assessment Report of the Intergovernmental Panel on Climate Change. (pp. 709–754). Cambridge University Press. https://www.ipcc.ch/site/assets/uploa

ds/2018/02/WGIIAR5-Chap11\_FINAL.pdf

https://www.who.int/sdhconference/r

Solar, O., & Irwin, A. (2010). A conceptual framework for action on the social determinants of health (Discussion Paper Series on Social Determinants of Health, Paper 2). World Health Organization.

esources/Conceptualframeworkforactio nonSDH eng.pdf

Tagalik, S. (2009-2010). Inuit Qaujimajatuqangit: The role of Indigenous knowledge in supporting wellness in Inuit communities in Nunavut. National Collaborating Centre for Aboriginal Health. https://www.ccnsanccah.ca/docs/health/FS-InuitQaujimajatuqangitWellnessNunavu t-Tagalik-EN.pdf

Tutton, M. (2012, September 10). Dikes burst in Truro as rain swamps N.S. rivers. *CTV* News. https://atlantic.ctvnews.ca/dikesburst-in-truro-as-rain-swamps-n-s-

rivers-1.949820

United Nations Human Rights Council. (2020, September 4). Visit to Canada: Report of the Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes (A/HRC/45/12/Add.1). https://undocs.org/en/A/HRC/45/12/ Add.1

Waldron, I. R. G. (2016, September 10). Experiences of environmental health inequities in African Nova Scotian communities. ENRICH Project. https://www.enrichproject.org/wpcontent/uploads/2016/10/Final-Environmental-Racism-Report.pdf

Waldron, I. R. G. (2018). There's something in the water: Environmental racism in Indigenous and Black communities. Fernwood Publishing.



## Research Article

## Student Perspectives on Indigenous Health Content in Pre-Clinical Medical Education

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#### **Abstract**

Introduction: In 2015, the Truth and Reconciliation Commission of Canada released 94 calls to action. These calls were intended to redress harms inflicted on Indigenous peoples as a result of the Indian Residential School system and to advance the process of reconciliation of Canada. Several of these calls to action are directed specifically toward educating health-care providers as a means to actively eliminate racism in health-care experiences for Indigenous peoples. **Objectives**: To identify the learning needs of pre-clerkship medical students with respect to Indigenous health content and curriculum, and to explore the perspectives of pre-clerkship medical students on existing gaps in the medical curriculum regarding Indigenous health. Methods: This study involved semi-structured interviews with 14 first- and second-year (pre-clinical/pre-clerkship) medical students at one medical school. Thematic analysis was performed using NVivo data management software to identify common themes, and then considered within the context of the existing literature. Results: Three main themes were identified: (a) Familiarity with Indigenous culture prior to medical school, (b) constructive criticism about Indigenous education in medical school, and (c) pervasive lack of education about Indigenous health issues in the program. **Discussion:** Participants felt they needed more time devoted to learning about Indigenous peoples' health, as there are many topics to explore. Most participants felt that their understanding of health issues impacting Indigenous peoples has not been sufficient in their primary, secondary, and post-secondary education to date and offered suggestions for improving the Indigenous health content in the medical school curriculum. These suggestions included providing the education earlier in the program, having Indigenous peoples involved in content creation and delivery, and ensuring all learners have sufficient opportunity to learn more about Indigenous peoples and their health. **Conclusion:** Through this research we gain a glimpse of how future medical providers are interpreting Indigenous health curriculum, and whether and how they intend to apply this education to their own future practice.

NOTE: While the term Aboriginal has been used in Canada and Australia, the term Indigenous is used in this paper as an all-encompassing term to speak of the diverse cultures and peoples who are the original inhabitants of Canada, as it is used globally (Indigenous Foundations, 2009).



#### Student Perspectives on Indigenous Health Content in Pre-Clinical Medical Education

The authors acknowledge that this research and writing has taken place on the unceded and ancestral territory of the Mi'kmaq. We pay our respects to these lands and waters and honour the treaties of Peace and Friendship.

In Canada, Indigenous peoples' experiences with health care are shaped by what is referred to as the double burden of racism and colonialism (Yeung et al., 2018). The 2015 Truth and Reconciliation Commission of Canada (TRC) has provided 94 calls to action to support reconciliation between Indigenous and non-Indigenous peoples in Canada, addressing the intergenerational trauma of the Indian Residential School (IRS) system. The TRC determined that removing barriers faced by Indigenous peoples when accessing health care at all levels (provider, institutional, and system) would positively influence the opportunities available for Indigenous peoples (McNally & Martin, 2017). In response to this, a number of medical schools in Canada have implemented mandatory curriculum community-based activities that focus Indigenous peoples' health issues as a way to improve the knowledge, skills, and attitudes necessary to shift away from racist and colonialist assumptions (Yeung et al., 2018; Zhou et al., 2012). However, we know very little about whether this type of curriculum is meeting the needs of medical students, and what their perceptions are regarding the curriculum they are receiving.

This study used thematic analysis to analyze semi-structured, qualitative interview data from medical school students in order to begin assessing both the education delivered to future health-care providers about Indigenous peoples and their health and the extent to which the TRC recommendations were being followed. In-depth interviews with pre-clerkship (first-and second-year) medical students at one school were used to (a) identify their learning needs with respect to Indigenous health content in the medical curriculum, and (b) determine their

perspectives on existing gaps in the medical curriculum in this regard. The goals of this study are to identify, document, and understand first-and second-year medical students' current knowledge, skills, and attitudes toward Indigenous health.

#### **Background**

In 2016, Indigenous peoples (First Nations, Inuit, Métis) constituted 4.9% of the total Canadian population, reflecting an increase from 3.8% in 2006 (Statistics Canada, 2017). The Indigenous population in Canada has been shown to be growing at a rate that is four times faster than non-Indigenous Canadians, which is thought to be a result of higher birth rates and increased self-identification compared previous generations (Statistics Canada, 2017). Indigenous peoples in Canada continue to persistent health disparities, experience including a lower life expectancy and increased risk of heart disease, diabetes, obesity, sexually transmitted infections, and suicide (Jacklin et al., 2014). There are various contributing factors for these health disparities: loss of culture, issues of self-governance, colonialism (historically and today), child apprehensions and out-of-culture adoptions by the state, and the residential school experiences many individuals and communities were exposed to and continue to experience today through intergenerational trauma (Wilson et al., 2018). Intergenerational trauma is a cumulative effect of IRS trauma that undermines the health and well-being of Indigenous peoples today (Bombay et al., 2014).

Given these issues, it is crucial that medical students obtain appropriate education and training that is well informed and patient centred so that they can develop the necessary skills to navigate health-care issues confronting Indigenous patients. It is important for future health-care providers to learn about the underlying communication issues that can adverselv affect the patient-physician encounter and how best to circumvent these, building confidence in their skill to deliver culturally-sensitive medical care, which is a basic human right (Yeung et al., 2018). Cultural



sensitivity in health-care encompasses understanding one's own culture, having open and compassionate communication, and listening to patients and families to better understand and incorporate their beliefs and values into their health-care management (Brooks et al., 2019). Cultural safety in health-care refers to a safe environment for people of all cultures and backgrounds, where their values and needs are understood and respected (Williams, 1999).

Encouraged and supported by the Canadian Medical Association (CMA), most universities in Canada have been working to expand their respective curricula to incorporate Indigenous health courses (Jacklin et al., 2014). The CMA Board of Directors has highlighted the importance of recognizing and addressing the impact of intergenerational trauma caused by the IRS system and supports the implementation of the TRC calls to action for medical learners and practising professionals (CMA Board of Directors, 2015, as cited in HealthCareCAN, 2016). Call to action #23 addresses the need for cultural competency training for all health-care professionals, and call to action #24 calls upon medical schools to require students to take a course about Indigenous health issues, the history and legacy of the IRS system, and other determinants of health impacting Indigenous peoples today (Truth and Reconciliation Commission of Canada, 2015).

It has been documented that medical students seem to be aware of "Indigenous health issues" generally, but they often have a more limited understanding of the socio-cultural and economic influences on these issues, as well as the intersectional way in which diverse factors such as poverty and racism may combine to affect the health of patients (Zhou et al., 2012). Without a nuanced understanding of the interrelationships between structural determinants that affect the health Indigenous peoples, it is unlikely that knowledge, skills, and behaviours will be fundamentally altered (Yeung et al., 2018), which raises questions as to whether simply increasing Indigenous content in medical curriculum is sufficient. To date, there has been

limited research to assess whether medical students feel that the education they are receiving is effective in transforming their ability and willingness to work with Indigenous patients in a culturally safe way. One issue is that medical students' knowledge about Indigenous peoples remains rooted in personal biases and negative medical and educational portrayals, which stems from the historical and ongoing effects of colonialism and anti-Indigenous racism in Canada and around the world (Ly & Crowshoe, 2015). This is also known as the "hidden curriculum," and many medical schools are attempting to reduce the biases that the hidden curriculum creates among their learners (Kidman et al., 2013). The first step in challenging these biases is for the learner to become aware of their own biases, learn about bias in the medical system, and be taught ways in which they can work toward reducing bias in their lives and practice.

#### **Study Objectives**

The purpose of the study was to address the following specific research objectives: (a) Identify the learning needs of pre-clerkship medical students with respect to Indigenous health content and curriculum, and (b) explore the perspectives of pre-clerkship medical students on existing gaps in the medical curriculum regarding Indigenous health.

#### Methodology

In this research study, the student researcher was non-Indigenous, but had previously completed an MA where the thesis research was done with an Indigenous community using narrative inquiry and Two-Eyed Seeing. The student researcher has also been part of several research projects and groups relating to Indigenous health promotion. The research supervisor is an Indigenous researcher. These experiences were used to establish the research questions, and to form questions and probing questions for the interview guide.

This exploratory study was guided by Interpretative Phenomenological Analysis, and



thematic analysis. Interpretative Phenomenological Analysis is a methodology that explores how participants derive meaning from their lived experiences (Pietkiewicz & Smith, 2014). It incorporates elements of phenomenology and other qualitative research methods, and involves self-reflection on the part of the participants and iterative reflection and immersion in the data on the part of the researcher. Phenomenology is a qualitative approach that is used to explore and find meaning from the lived experiences of a specific group of people (Hall et al., 2016).

Data was collected using structured interviews and analyzed using thematic analysis (Braun & Clarke, 2021). The call for participants was done via a one-slide presentation with the study details and contact information for the lead researcher. Participants were selected according to the following shared traits: (a) enrolled in one specific university's MD program, and (b) are first- or second-year medical students. This population was selected because their learning during pre-clerkship vears is done mainly in the classroom and is standardized for all students in the class, which is not the case for clerkship training in years 3 and 4. Participants included 14 medical students (six in first year; eight in second year). Institutional Review Board approval was obtained, and informed consent was obtained before data collection commenced.

Semi-structured interviews were used to gain an in-depth understanding of medical students' perspectives. This interview guide was piloted with three students in their third year of medicine, who were ineligible for the study but had been taught using similar lectures and sessions. The following is an example question from the interview guide, along with probing questions for follow up:

1) What training/education have you received (if any) regarding Indigenous health? [Probes: Ask about formal education in classrooms/research, but also about informal learning opportunities: lived experiences, volunteering, interest groups, public lectures/events, etc.]

The interviews were conducted in person and audio-recorded at the university in a privately booked study room. An appropriate number of participants were interviewed, and study objectives were deemed to have been met. Recruitment was then ceased, and no further interviews were done. After the interview responses were transcribed, coding and thematic analysis were performed using NVivo data management software. Here, the goal was to identify themes within individual participant responses and within the entire data set using thematic analysis. Thematic analysis is an approach to identifying, analyzing, reporting qualitative data and the patterns, or themes (Braun & Clarke, 2006). There are six phases of conducting thematic analysis, which are as follows:

- 1. Familiarizing yourself with the data,
- 2. Generating initial codes,
- 3. Searching for themes,
- 4. Reviewing themes,
- 5. Defining and naming themes, and
- 6. Producing the report.

The resultant themes were then considered from multiple angles and discussed in the context of the existing literature.

#### **Findings**

Three major themes were derived upon analysis of the interviews. They are related to the participants' previous and current knowledge of Indigenous peoples and their health, the students' perception of their medical school's Indigenous health curriculum, and the pervasive lack of education about Indigenous health issues.

# Familiarity with Indigenous Culture Prior to Medical School

Most participants said that, at one point in their lives, they had lived in close proximity to an Indigenous community. None self-identified as being Indigenous. For instance, one participant notes that they went to high school with First Nations people from a nearby community, and that some of the high school



curriculum was shaped by an Indigenous teacher:

There was a reserve close to my high school, and their students went to my high school. That would be my only real experience with an Aboriginal community. They would be in our classes and there was actually a Mi'kmaw teacher—one of the teachers was Mi'kmaw. He actually started a Mi'kmaq studies class when I was in my grade 12 year. He was really cool. - First-Year Student

Although many participants in the study noted that they may have encountered Indigenous peoples during high school, this did not necessarily mean that the interactions led to strong cross-cultural relationships or that they were free from racism.

My high school was a little racist. For example, there was one girl, a White girl, who was dating a First Nations boy, and everyone kind of made fun of her for that and called her bad names. It was also very much like, if you look in the cafeteria you can see Native kids at one table, you know, sitting separated like that from the other kids. – First-Year Student

Without being provided historical background and context, the lived experiences of the participants in the study may not have offered opportunities to break down stereotypes or to understand the barriers faced by Indigenous peoples. As the next participant describes, the first time they were exposed to Indigenous issues was during medical school.

I think a lot of people haven't been exposed to Aboriginal health care issues before medicine at all. I was an interviewer this year for [Medical School] and I had a question surrounding Aboriginal health and I was blown away at how little some people knew. I would probably have been in the same situation. I never intentionally learned about it in high school or before med school. – Second-Year Student

As the participant explains, while questions about Indigenous health may be included in the interview for incoming medical students, the interviewer or actor may not have a deep understanding of the topic, despite being in medical school themselves.

#### Indigenous Education in Medical School— Constructive Criticism

The second major theme pertains to the content and delivery of Indigenous health lessons in the medical school curriculum. The participants had differing perspectives about this. For example, many participants discussed the sessions dedicated to Indigenous health in the curriculum in a positive way:

Well, we had two weeks of pro-comp [Professional Competencies is a course that is delivered once each week] dedicated to Aboriginal health. Both sessions were mostly led by Aboriginal people and then we had each lecture followed by two hours of, like, a normal pro-comp tutorial. But we also had Aboriginal coach tutors. Every group had an Aboriginal community member in their group sessions. I think they [the sessions] went really well, at least a lot of them ... I think a lot of people did learn a lot from them. – Second-Year Student

We can see from the next participant, however, that the effectiveness of these sessions is subjective to each student or group of students. While they agreed on number of days in which Indigenous health content was delivered, one of the participants noted that they felt the Indigenous content was not embedded into other curriculum content areas, making it feel siloed:

[We] only get a day or two days for Indigenous health, and then we have a day of Refugee health, ... and it's like we have these days that are pretty siloed, even though they're all part of the [same] course, and most is in second year. – Second-Year Student



Another participant makes a strong case for starting the Indigenous content earlier in the medical school curriculum, and this was brought up by many participants. It is worth noting, however, that this institution's curriculum has made changes since these data were collected in 2018, with this curriculum now being offered earlier. As described in the TRC calls to action, medical schools have a duty to introduce this new aspect of the curriculum in the right way so that students are able to build upon skills of cultural competency throughout their education.

We can't assume that everyone knows [about] Aboriginal health. And certainly, things like the residential schools and how reserves are structured, how health care is provided and funded to Indigenous populations, to drug coverage and access, which are all very different for Indigenous peoples. Those are all things that really need to be laid out and given to us in a direct, explicit sort of way, early on. – First-Year Student

# The Lack of Education About Indigenous Health Issues is Pervasive

Medical students, much like the general population, have not had adequate education about Indigenous history and health issues in primary school, secondary school, or during their undergraduate education. Many students are encountering these concepts and learning about the social determinants of health that impact Indigenous health for the first time in medical school, which is not soon enough for some patient encounters.

It's strange we get to see patients for a year, or actually a year and a half, as medical students without having, you know, a basic understanding of who lives in our province/region and how to be culturally competent. – Second-Year Student

As described in the TRC calls to action, medical schools are to teach their students about Indigenous health issues, the history and legacy of the IRS system, and other determinants

of health impacting Indigenous peoples today. The goal of introducing students to these concepts is to create future health-care providers who are able to deliver culturally safe care to all of their patients.

There is also an element of reconciliation that universities have a duty to provide that by making space in the curriculum for these issues. That is one way that universities, which are a relic of colonialism and privilege in the Americas, can make steps towards reconciling. These are things that graduates need to learn because they will make them better doctors and better able to provide for their patients. That's one thing, and then two, it is a moral ethical obligation to educate students and doctors on these issues as a means of reconciliation. – Second-Year Student

The TRC call to action #23 also calls for an increased number of Indigenous health-care providers to be trained, and this need was noticed by participants in the lack of diversity observed in their instructors.

I really don't feel like it's been presented well at all. You know, even if you look at our lecturers it has been a lot of very White people, and even the diversity among lecturers or tutors that we have seen is not nearly enough. I haven't met a single First Nations person either as a lecturer or preceptor yet, a year in. It's not only the content that's lacking but also the representation. – Second-Year Student

As participants began to learn about the historical and current injustices and health disparities faced by Indigenous peoples, they noted feeling frustrated about how little they know about such an important issue. The result of this frustration is that some were finding creative solutions to supplement their existing curriculum with additional learning opportunities, such as student-led organizations and volunteer opportunities.



I would say I've had very little education around Indigenous health in any sort of formal way. In the first-year med school curriculum it's touched on a little bit, but it feels rather tokenistic ... There have been opportunities to learn about it outside of the classroom. So, I participate in the Indigenous Health Interest Group and there have been opportunities to engage with health issues there that have been very valuable. – First-Year Student

#### Discussion

The findings in this study relate to medical students' knowledge about, and current and past education relating to, Indigenous health in Canadian medical schools. While participants were keen to learn more about Indigenous health, there has been limited opportunities for them to do so in a meaningful way. Similar to Sylvestre et al. (2019), the participants in this study agree that without ample opportunity to interact with Indigenous patients and to learn about how structural determinants interact to affect the health of Indigenous peoples, there is concern among students that they risk reinforcing anti-Indigenous racism.

While many participants had some experiences with and education regarding Indigenous health issues before entering medical school, these were not always positive. Students expressed awareness of the individual racism Indigenous people encounter but recognized that they had little intentional learning on Indigenous history, culture, and health issues or the structural and systemic racism embedded in colonial education and health care systems. This theme of familiarity with Indigenous cultures is important for predicting students' future interest developing their practices (Margolius Bodenheimer, 2010). It is imperative that medical practitioners be equipped with more than adequate knowledge and competence to address the health-care needs of Indigenous peoples in Canada. Having Indigenous scholars and community members create and deliver the

curriculum is one way in which this gap in previous education can be addressed.

Participants felt that two days of Indigenous content in second year is not enough. Students generally found the Indigenous curriculum delivery to be a positive experience, but also limited in how it is integrated into other aspects of curriculum and how it is framed and built upon over the course of the two-year preclerkship curriculum. As Jacklin et al. (2014) notes, there are significant challenges in "new" providing education to students—largely in the negotiation of curricular time. Additionally, there is a significant need to recruit Indigenous healthcare professionals and educators to develop and deliver this content to students (Zhou et al., 2012). Participants noted that the lack of education about Indigenous health is not limited just to medical students but is pervasive within Canadian society. As such, it is imperative that the education one receives in medical school addresses this learning gap, so that future providers are well informed and able to be competent physicians for all of their future patients. It is recommended that medical schools ensure they are introducing these topics earlier and more regularly to students, as they then gain time and opportunities with which to practice their skills, as well as explore elective and other learning opportunities relating to Indigenous health and well-being throughout their training, aided by early exposure to these topics and communities. Medical students are also then better prepared to combat pre-existing stereotypes that students may have and create more culturally-aware and safe practitioners (Ly & Crowshoe, 2015). Some students with a pre-existing interest in Indigenous health are seeking out their own extra-curricular learning opportunities to supplement the curriculum. However, this means that students without this interest, who may know very little about Indigenous peoples and their health, are not exposed to these opportunities and therefore have very few opportunities to counter preexisting stereotypes and assumptions.



#### **Study Limitations**

Limitations to this study include the possibility that the students who volunteered to participate may have an interest in Indigenous health and therefore may not be representative of the entire medical school class. Another limitation is that the lead researcher was known to the participants, and this may have altered the responses provided to be more socially acceptable.

Since these data were collected, there have been significant changes made to the Indigenous health content in the medical school curriculum, which were created and delivered by an Indigenous professor. A comparative study evaluating students' perspectives during their education and at graduation could be used to compare the relative efficacy of this new content.

#### Conclusion

In this study, we found that among preclerkship medical students, Indigenous health is a topic seen as important for the future practice of physicians and one that needs to be improved upon within the medical school curriculum. Since the TRC calls to action include the education of future health-care providers, this study sought to document and explore existing students' perspectives on Indigenous health in one medical school's curriculum and offer suggestions for improving the experience for students. We also found that many students had some familiarity with Indigenous cultures prior to medical school, but that this was often inadequate and not based on formal education on the subject. Students were able to evaluate the education they had received thus far in medical school regarding Indigenous health, and they had suggestions for improvement. The lack of education about Indigenous health issues is a pervasive issue that is best addressed with interventions: providing quality several education earlier in the medical school curriculum as part of reconciliation, having Indigenous peoples involved in developing and teaching this content, and ensuring all medical

students are exposed to informative and engaging Indigenous health learning opportunities.

#### References

- Bombay, A., Matheson, K., & Anisman, H. (2014). The intergenerational effects of Indian residential schools: Implications for the concept of historical trauma. *Transcultural Psychiatry*, *51*(3), 320–338. https://doi.org/10.1177%2F13634615 13503380
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.
- Braun, V., & Clarke, V. (2021). One size fits all?
  What counts as quality practice in
  (reflexive) thematic analysis?
  Qualitative Research in Psychology,
  18(3), 328–352.
  https://doi.org/10.1080/14780887.20
  20.1769238
- Brooks, L. A., Manias, E., & Bloomer, M. J. (2019). Culturally sensitive communication in healthcare: A concept analysis. *Collegian*, *26*(3), 383–391. https://doi.org/10.1016/j.colegn.2018. 09.007
- Hall, E., Chai, W., & Albrecht, J. A. (2016). A qualitative phenomenological exploration of teachers' experience with nutrition education. *American Journal of Health Education*, 47(3), 136–148. https://doi.org/10.1080/19325037.20 16.1157532
- HealthCareCAN (2016). Issue brief: Truth and Reconciliation Commission of Canada: Health-related recommendations. https://www.healthcarecan.ca/wp-content/themes/camyno/assets/document/IssueBriefs/2016/EN/TRCC\_EN.pdf
- Indigenous Foundations (2009). *Terminology:*So, which terms do I use? First Nations & Indigenous Studies, University of British Columbia.
  https://indigenousfoundations.arts.ubc.ca/terminology/



- Jacklin, K., Strasser, R., & Peltier, I. (2014). From the community to the classroom: The Aboriginal health curriculum at the Northern Ontario School of Medicine. *Canadian Journal of Rural Medicine*, 19(4), 143–150.
- Kidman, J., Yen, C.-F., & Abrams, E. (2013).
  Indigenous students' experiences of the hidden curriculum in science education:
  A cross-national study in New Zealand and Taiwan. International Journal of Science and Mathematics Education, 11(1), 43–64. https://doi.org/10.1007/s10763-012-9365-9
- Ly, A., & Crowshoe, L. (2015). 'Stereotypes are reality': Addressing stereotyping in Canadian Aboriginal medical education. *Medical Education*, 49(6), 612–622.
- https://doi.org/10.1111/medu.12725
  Margolius, D., & Bodenheimer, T. (2010).
  Transforming primary care: From past practice to the practice of the future. *Health Affairs*, *29*(5), 779–784. https://doi.org/10.1377/hlthaff.2010.0 045
- McNally, M., & Martin, D. (2017). First Nations, Inuit and Métis health: Considerations for Canadian health leaders in the wake of the Truth and Reconciliation Commission of Canada report.

  Healthcare Management Forum, 30(2), 117–122. https://doi.org/10.1177/0840470416680445
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7–14.
- Statistics Canada. (2017, October 25).

  Aboriginal peoples in Canada: Key results from the 2016 Census. https://www150.statcan.gc.ca/n1/daily-quotidien/171025/dq171025a-eng.htm
- Sylvestre, P., Castleden, H., Denis, J., Martin, D., & Bombay, A. (2019). The tools at their fingertips: How settler colonial geographies shape medical educators'

- strategies for grappling with Anti-Indigenous racism. *Social Science & Medicine*, *237*, Article 112363. https://doi.org/10.1016/j.socscimed.2019.112363
- Truth and Reconciliation Commission of Canada (2015). Truth and Reconciliation Commission of Canada: Calls to action. https://ehprnh2mwo3.exactdn.com/wp-Content/uploads/2021/01/Calls\_to\_Action\_English2.pdf
- Williams, R. (1999). Cultural safety—what does it mean for our work practice?

  Australian and New Zealand Journal of Public Health, 23(2), 213–214.

  https://doi.org/10.1111/j.1467-842X.1999.tb01240.x
- Wilson, N., Ewen, S., & Mazel, O. (2018). Medical students in Aboriginal Community Controlled Health Services: Identifying the factors involved in successful placements for staff and students. *Australian Medical Student Journal*, 8(2), 26–30. http://www.amsj.org/archives/6330
- Yeung, S., Bombay, A., Walker, C., Denis, J.,
  Martin, D., Sylvestre, P., & Castleden, H.
  (2018). Predictors of medical student
  interest in Indigenous health learning
  and clinical practice: A Canadian case
  study. *BMC Medical Education*, 18(1),
  Article 307. https://doi.org/10.1186/
  s12909-018-1401-1
- Zhou, A. W., Boshart, S., Seelisch, J., Eshaghian, R., McLeod, R., Nisker, J., Richmond, C. A. M., & Howard, J. M. (2012). Efficacy of a 3-hour Aboriginal health teaching in the medical curriculum: Are we changing student knowledge and attitudes? Health Education Journal, 71(2), 180–188. https://doi.org/10.1177% 2F0017896910394544



## Research Article

# Physician Burnout in Canada: Challenges and Possible Future Interventions

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#### **Abstract**

**Background:** Physicians are the backbone of the health-care industry, and the state of their wellbeing significantly influences the productivity, financial conditions and overall performance of the health care system. The objectives of this literature review are to highlight the challenges posed by physician burnout to the Canadian health care system and suggest possible recommendations to reduce this burnout. Methods: Database searches were conducted to study the effects of physician burnout on the health care system. Websites of organizations like the Canadian Medical Association, Canadian Medical Protective Association, Canadian Collaborative Centre for Physician Resources and Medical Council of Canada were searched. Research papers from Canada, the United States, Europe and Hong Kong were assessed to support the existence of burnout among physicians in Canada and globally. Results: Burnout affects the Canadian health care system in terms of estimated cost, patient safety, productivity, performance, COVID-19 pandemic response and future medical workforce supply. It was found that the level of physician burnout is increasing notably among the Canadian workforce, with the COVID-19 pandemic adding more stress to the situation. The costs of burnout rendered to the health care system are continually increasing each year in Canada. Many physicians across the world are considering retiring early, while others are considering quitting the profession altogether, adding to the pressure already imposed on the physicians remaining in the system. Recommendations to reduce burnout among physicians from the literature were studied as part of this review. **Conclusion:** Physician burnout has several negative impacts on the health care system. This literature review provides a concise overview of the major challenges posed by burnout among Canadian physicians. It will help contribute to plans and strategies to reduce physician burnout in the future.



# Physician Burnout in Canada: Challenges and Possible Future Interventions

#### Introduction

Burnout among health professionals is not only common in Canada but has become more of a global issue in recent years (Dewa, Jacobs, et al., 2014). Interest in studying this phenomenon is increasing because of its heavy impact on health care outcomes and the dire need to overcome associated challenges (Shanafelt et al., 2017). Physician burnout is characterized by three symptoms: exhaustion, depersonalization and lack of efficacy (low sense of personal accomplishment; Drummond, 2015). Burnout also claims its victims in a personal manner with regard to higher risk of alcohol abuse and dependence and an associated increased risk of suicidal ideation (Dyrbye et al., 2008). The numerous stresses of the job, along with the typical ideology of not exhibiting fatigue, contribute to burnout becoming an inevitable outcome for all physicians (Boyle, 2018). There have been many studies conducted in the past to better understand the causes of physician burnout in Canada (Dewa, Jacobs, et al., 2014). Over the years, Canadians have been experiencing increasing wait times to access medical services, and it has been a major contributing factor to the burden on the health care system (Dewa, Jacobs, et al., 2014). The purpose of this literature review is to outline the major challenges that physician burnout poses to the health care system in Canada as well as to offer possible recommendations to reduce this burnout.

#### Methods

For the purposes of this rapid review, a systematic search of both grey and published literature was performed. The databases that were searched included PubMed, MEDLINE, Google Scholar and PsycInfo. Websites of organizations like the Canadian Medical Association (CMA), Canadian Medical Protective Association, Canadian Collaborative Centre for Physician Resources (C3PR) and Medical

Council of Canada were also searched. Examples of keywords used to conduct the search included "physician," "burnout," "patient safety," and "COVID-19." Only papers written in English and focusing on physician burnout from a national perspective were included. Papers regarding burnout in other medical professions (e.g., nursing) were excluded.

The search strategy conducted for this review produced 19 papers that met the inclusion criteria. Eleven of these research papers were from Europe and the United States, and the remaining eight were from Canada. Standard rapid review procedures (Dobbins, 2017) were followed with respect to database searches and article translations. Recommendations were extracted from the literature and personal recommendations were also articulated for the purposes of this paper.

#### **Results**

# Estimated Cost of Physician Burnout in Canada

A study conducted by Dewa, Jacobs et al. (2014) helps in establishing an estimate of the cost of burnout associated with Canadian physicians. It utilized an economic model and was supported by data from National Physician Surveys. Physician data was analyzed on the basis of their specialty, weekly work hours, patient load per hour and patient visits per week. The cost of early retirement was based on the annual loss of physician revenue and the result was an estimated loss of \$118.53 million (2010 CAD\$) per year from family physicians retiring early. Loss of revenue due to early retirement of surgeons was estimated to be around \$33.68 million, and from other specialists, \$32.96 million. On the other hand, the cost of reduction in clinical hours was calculated by estimating the reduction in visits per week using the difference in weekly visits between dissatisfied and not dissatisfied physicians. An estimated \$6.8 million was projected to be lost from family physicians reducing their clinical hours. The total cost of burnout for all physicians in Canada was estimated to be \$213.1 million, presented as a



future value of service reductions (Dewa, Jacobs, et al., 2014). The future value is a discounted value calculated to estimate the time value of dollars in the future (Vo, 2019). This estimate is conservative because it is calculated as the difference in costs for physicians who experienced burnout versus the costs if those physicians did not experience burnout (Dewa, Jacobs, et al., 2014).

# Relationship Between Physician Productivity and Burnout

A paper by Dewa, Loong, et al. (2014) includes a systematic literature review of five studies conducted in the US, China, Hong Kong, the Netherlands, the United Kingdom and 11 other European countries. Global reports suggest that burnout results in low job satisfaction, deteriorating mental health and poor quality of care (Dewa, Loong, et al., 2014). All these outcomes impact the level of productivity in the workplace. Burnout was measured using the Maslach Burnout Inventory-Human Services Survey (Maslach & Jackson, 1981). Productivity was measured and outcomes discussed using the following four parameters: sick leave, intent to change jobs, intent to quit practising medicine, and work ability (Dewa, Loong, et al., 2014). With regard to the first outcome of sick leave, the study from the European countries suggested that all three symptoms burnout (exhaustion, of depersonalization and lack of efficacy) are significantly associated with more use of sick days (Soler et al., 2008). In contrast, Siu et al. (2012) reported no statistically significant differences in the average sick leave days in the past year for public hospital physicians with and without high burnout scores. There are conflicting results reported for this parameter because productivity measures and working styles are different for each individual (Dewa, Loong, et al., 2014). Secondly, the intent to change jobs was strongly associated with high burnout scores. The intent to quit practising medicine was the third outcome and qualified as a strong indicator of burnout among physicians. The fourth outcome was of work ability and was defined by Ruitenburg et al. (2012) as "the

degree to which a worker is physically and mentally able to cope with the demands of the work" (p. 2). Focusing on Canada, the CMA's annual Physician Resource Questionnaire in 2002 revealed that physicians worked an average of 53.8 hours per week, excluding oncall activities, compared with 53.4 hours in 2001 and 52.9 hours in 2000 (Martin, 2002). The 2002 survey was mailed to a random sample of 7,693 doctors, and the response rate was 38%. Of these physicians, 9% reported reducing the scope of their practice in the last two years to reduce the workload and increase productivity (Martin, 2002). Several of these physicians reported being dissatisfied with their lifestyle, with an increasing patient load and less time to spend with their families (Martin, 2002). The responses signified a rising need to incorporate measures to reduce burnout among these physicians.

#### **Effect of Burnout on Patient Safety**

There are a number of studies conducted across North America and several surveys done in Canada that suggest burnout and patient safety have a negative relationship (Salyers et al., 2017). The meta-analysis conducted by Salyers et al. suggests that there is a statistically significant decrease in patient safety and quality of care with increasing burnout among of physicians. The meta-analysis the relationship between burnout and patient safety included 40 independent samples and resulted in a significant negative relationship (r = -0.23). with a confidence interval of 95% ranging from -0.28 to -0.17. It was also noted that emotional exhaustion is likely the most critical element of burnout to address (Salyers et al., 2017). According to the Canadian Medical Protective Association, burned-out physicians reported taking shortcuts, failed to follow established procedures, did not answer patient questions, did not discuss treatment options, and made treatment errors that could not be attributed to a lack of knowledge (The Canadian Medical Protective Association, 2018a). shortcomings translated to poor quality of care along with longer recovery times among patients, which, in turn, increased waiting times.



When looked at from the perspective of the building blocks of health care systems, burnout is responsible for negatively impacting service delivery, health care workforce and financing (World Health Organization, 2010).

# Impact of Burnout on Health System Performance

According to Sinsky et al. (2017), physicians are exiting their careers in medicine faster than they enter; their intentions to withdraw are highly correlated with burnout with an odds ratio of 5.8. This suggests that there will be a severe shortage of practising physicians in the near future. This negative impact on the health system performance is directly related to burnout and can be averted if due attention is paid to it. The prevalence rate of burnout in the United States is only 2.6 times the rate of that in Canada, even though the physician workforce in the United States is 12 times bigger (Sinsky et al., 2017). A survey was conducted in the United States in 2014 (Sinsky et al., 2017). Out of the 6,695 physicians in clinical practice in the US at the time of the survey, 19.8% of those who responded reported it was likely or definite that they would reduce clinical work hours in the next 12 months, while 26.6% indicated it was likely or definite that they would leave their current practice in the next two years (Sinsky et al., 2017). This demonstrates the prevalence of burnout in the United States causing physicians to either quit the profession or reduce work hours. It is important to note that even with Canada's smaller physician workforce, the burnout rates are much greater than expected (Sinsky et al., 2017). This burnout is increasing because physicians are physically present but psychologically withdrawn, the result being major effects on patient health outcomes, efficiency and productivity (Olson, 2017). All these factors together constitute the overall health system performance. In a survey conducted by the CMA in 2017, it was found that 74% of family/general physicians were partially or completely closed to accepting new patients (CMA, 2017). An interpretation of this result suggests that patient load is constantly increasing in Canada, adding to the rising levels

of burnout among Canadian physicians and the deteriorating quality of health-care service delivery.

#### Physician Work Hours in Canada

As seen in Table 1, physician work hours in Canada have been relatively consistent over the years (CMA, 2017). However, Canadian Medical Protective Association data shows that over the past five years, college and hospital complaints have risen by more than 20%, and burnout may be associated with this increase (The Canadian Medical Protective Association, 2018b). Moreover, the CMA conducted an online survey in 2017 with almost 3,000 physicians and residents. According to its findings, one in three Canadian physicians screened positive for depression (Boyle, 2018), and a significantly higher number of residents reported burnout and depression than physicians (CMA, 2018). The CMA President also raises the issue of prevailing stigma in the field, which prevents many health professionals from seeking help (Boyle, 2018). In order to reduce burnout in Canada as well as globally, the first step is to remove these stigmas from the health care environment. Despite being mentally, physically and emotionally exhausted, physicians continue to work, resulting in more medical errors that consequently increase health care costs.

# Effect of the COVID-19 Pandemic on Physician Burnout

In light of the COVID-19 pandemic, the situation of burnout among Canadian physicians has become even worse. There is a national shortage of emergency medical professionals in Canada, and on top of that, 86% of those currently practising emergency medicine experience burnout (Chochinov & Lim, 2020). The pandemic superimposed on the already dysfunctional emergency departments Canada is proving to be one of the biggest crises the health industry needs to combat. Moreover, the pandemic is exhausting physicians to the brink of considering suicide, and access to toxic medication is increasing the risk (Gulati & Kelly, 2020). There are several instances in which a physician may suffer from moral injuries:



Table 1 Average Hours Worked per Week by Canadian Physicians, 1997–2017

cma.ca | amc.ca

## Average hours worked per week by physicians, 1997-2017

	1997	1998	1999	2000	2001	2002	2003	2004	2007	2010	2014*	2017*
Activity	n=3350	n=3285	n=3050	n=2734	n=3123	n=2763	n=2173				n=9423 N=66241**	n=6601 N=69433**
Direct patient care	35.6	36.2	35.9	35.0	35.0	35.6	35.4	34.0	33.3	32.7	31.0	33.0
Health facility committees	1.5	1.3	1.4	1.2	1.3	1.2	1.2	0.8	1.0	0.8	0.9	0.9
Managing practice	2.2	2.0	2.4	2.3	2.2	2.5	2.2	1.5	1.6	1.6	1.5	1.4
Other indirect patient care	4.5	4.5	4.9	5.1	4.8	5.0	5.2	5.3	5.9	6.1	6.2	6.9
Research	1.6	1.6	1.6	1.6	1.8	1.7	1.5	1.5	1.6	1.6	1.3	1.2
Administration	2.1	2.2	2.3	2.2	2.3	2.0	1.8	2.2	2.2	2.5	2.4	2.3
Teaching/educating without direct patient care	1.6	1.5	1.4	1.4	1.6	1.6	1.4	1.2	1.5	1.6	1.6	1.4
Continuing medical education	2.9	2.9	3.0	3.0	3.1	3.2	3.0	3.1	3.2	3.2	3.0	2.6
Other activities	1.2	1.1	1.2	1.1	1.2	1.1	1.2	1.1	1.2	1.3	0.8	0.9
Total	53.2	53.4	54.1	52.9	53.4	53.8	52.9	50.7	51.7	51.4	48.7	50.5

Excludes time spent on-call; Includes full-time, part-time, and semi-retired physician respondents

\*Excludes those who abandoned the survey prior to this question.

\*\*The responding sample (size: n) has been weighted to represent the population (size: N).

ource Questionnaire, Canadian Medical Association 1997 - 2003 P

2004, 2007, 2010, 2014 New Line College of Family Physicians of Canada, Canadian Medical Association, The Royal College of Physicians and Surgeons of Canada

, Canadian Medical Association

Note. From Average hours worked per week by physicians, 1997–2017, by CMA, 2017.

situations where there are ethical conflicts regarding which patients to admit (Parker & Mirzaali, 2020) or where physicians are professionally isolated due to reduced access to peer groups and social distancing protocols (Gulati & Kelly, 2020). Overall, physician burnout has never been worse globally and there is a growing need to provide support to these physicians. Some suggestions made by Gulati and Kelly include hospitals being made to establish a COVID-19 Clinical Ethics Committee (Gulati & Kelly, 2020). Physicians should be able and even required to have meetings with this committee on short notice in order to be supported in the clinical decisions they make (Gulati & Kelly, 2020). This would reduce the burden of responsibility on individual physicians and relieve some symptoms of burnout. Secondly, in accordance maintaining social distancing, physician peer groups should hold regular virtual meetings that allow physicians to discuss their problems. Such informal sessions can prove to be of utmost significance in fighting the challenges associated

with professional isolation (Gulati & Kelly, 2020).

#### **Recommendations to Reduce Physician Burnout from the Literature**

Burnout and depression have been identified in almost half of all practising physicians in Canada (Boyle, 2018). In a study conducted by Kuhn and Flanagan (2017), it is suggested that, due to increasing work demands, physicians feel there are fewer opportunities to appreciate the patient-doctor relationship that historically was a privilege of medicine. A few steps outlined in this paper to overcome burnout in Canadian physicians include promoting mindfulness and teamwork for trainees and physicians, developing practice models that preserve physician work control, supporting manageable patient panel sizes, promoting career opportunities advancements for physicians, and prioritizing self-care as part of medical professionalism (Kuhn & Flanagan, 2017). It is essential to the well-being of physicians to engage in self-care



practices, beginning with reporting and seeking help for stress associated with workload. Institutional metrics should be including a greater focus on physician satisfaction and wellbeing in their reports and research agendas. Physicians should be given sufficient control over their work hours and the length of patient visits to maintain a healthy work-life balance. Issues like added stress from maintaining electronic health records should be investigated, and staffing in such clinics should be increased to battle the extra workload placed on physicians (Kuhn & Flanagan, 2017). While medical boards and credentialing services focus on diagnosing depression among medical professionals (Kuhn & Flanagan, 2017), they should be working on encouraging physicians to seek help without the concerns of facing licensure limitations. A more result-oriented approach can include the formation of a committee focused on physician wellness, with its sole purpose being mobilization of more resources to educate medical professionals about burnout and suggest strategies to combat the same.

While many physician-directed interventions are being suggested, a systematic review and meta-analysis is conducted by De Simone et al. (2019) to evaluate effectiveness of organizational strategies to reduce physician burnout. There are several issues related to work environment and organizational culture that affect physicians in a negative manner. Modifying staffing schedules in order to reduce physician shift hours (Garland et al., 2012), developing targeted quality improvement projects (Linzer et al., 2015), implementing changes in workflow, and designating periods of protected time slots where physicians and residents are required to de-stress (Shea et al., 2014) are some of the organizational interventions discussed in the systematic review. Organization-directed interventions were associated with a medium reduction in burnout score (Standardized Mean Difference of -0.446 with a 95% Confidence Interval ranging between -0.619 and -0.274), while physician-directed interventions were associated with a small reduction in burnout

score (Standardized Mean Difference of -0.178 with a 95% Confidence Interval ranging between -0.332 and -0.035; De Simone et al., Evidently, organization-directed interventions had a stronger impact on reducing burnout among physicians, since the strategies were applied on a larger scale and included improving the basic organizational workflow. To further discuss management of burnout in physicians, Panagioti et al. (2017) conducted a meta-analysis on randomized clinical trials and controlled before-after studies of interventions targeting burnout in physicians. This study further supports the results drawn from the study conducted by De Simone et al. (2019). It is stated that organization-directed interventions are more effective in diminishing the symptoms of burnout in physicians; however, such interventions are relatively rare (Panagioti et al., 2017). A total of 19 studies were analyzed by Panagioti et al. to assess effectiveness of controlled interventions in addressing physician burnout. Forty percent of these studies focused on organization-directed interventions like workload evaluations, discussion meetings to enhance teamwork, and structural changes in the organization to support physician wellness (Panagioti et al., 2017). Moreover, there were differences in burnout outcomes for physicians working in different health-care settings like primary or secondary care. Interventions in primary care had small to medium reductions in burnout, whereas interventions in secondary care were associated with small significant reductions in burnout. Thus, the overall results were similar to the ones revealed by De Simone et al. (2019), which signifies the need to strengthen organization-directed interventions in health-care settings.

#### **Author's Recommendations**

The Canadian health care system is considered one of the best in the world (Ireland, 2021), but it has some shortcomings. Due to shortage of medical staff throughout the country, burnout among medical professionals is continuously increasing. When examined from a deeper perspective, the root of the



problem lies in the scarcity of medical infrastructure. There are very few teaching facilities for medicine in the country. Thus, many medical students take up their careers in other countries like the United States (Slade, 2014). This results in a loss of potential medical workers in the Canadian health care system and causes a shortage of supply (Sinsky et al., 2017). A potential recommendation regarding this issue is for governments to increase the investment in more medical facilities and teaching institutes in Canada. That, in turn, will produce more future medical professionals who intend to work in this country. It will also help in reducing the workload of existing physicians and discouraging them from retiring early or reducing their current work Furthermore, it was observed that the concept of electronic health records is relatively new in Canada and has become a source of major burnout among physicians. The use of technology requires a fair amount of experience, and many elderly physicians are facing unnecessary stress due to lack of technology skills (Kuhn & Flanagan, 2017). This problem can be overcome by introducing specialists like medical transcriptionists who are professionally trained to maintain electronic health records. The excess of workload related to this particular task can be removed from physicians' daily duties and can aid in reducing burnout.

Moreover, the problem of physician shortage in Canada can also be attributed to the cumbersome process that internationally trained physicians must navigate in order to join Canadian workforce. As discussed the previously, there is a huge outflow of potential medical workers due to lack of teaching facilities in Canada. To combat this outflow, a potential solution includes bringing physicians from other countries into Canada. However, the process for international medical graduates (IMGs) to enter Canada and successfully practise medicine is particularly cumbersome. They are required to appear for several examinations including the Medical Council of Canada Qualifying Examination and complete their medical residency again, even if they have already done so in their home country (Medical Council of Canada, n.d.). This poses as a huge barrier for foreign physicians who are considering choosing Canada to build their careers. The only way to overcome this barrier is by re-evaluating the medical entrance procedure and somewhat modifying it to resemble the British system. In the UK, IMGs can take the Professional and Linguistic Assessments Board tests, as well as the Membership of the Royal Colleges of Physicians of the United Kingdom test, and start a training job in the National Health Service of the United Kingdom (Ivan, n.d.). This gives IMGs a way to support themselves in a new country while working toward building their medical career without having to pursue a residency. After working the training job for two to three years, they can apply for their specialist/GP registration and continue practising medicine (Ivan, n.d.). If a system like this is implemented in Canada, many IMGs will start choosing Canada to build their medical career. There will be a consistent inflow of new physicians, further reducing the problem of burnout in the country.

Several supporting studies and surveys have been conducted in the past to better understand the problem of physician shortage and burnout in Canada. In the 1970s, Canada had a growing physician population, which resulted in a physician-to-population ratio of 1.91/1,000 in 1993 (CMA, 2013). However, the federal government realized that there was a surplus of physicians, and subsequently implemented policies to control this growth (Malko & Huckfeldt, 2017). The policies caused the net inflow of physicians into the physician pool to drop from 1,040 physicians per year in the period of 1990–1993 to 313 physicians in the period of 1994-2000 (Chan, 2002). The government then made efforts to increase the physician population. However, despite the efforts, the physician-population ratio in Canada was 2.24/1,000 in 2014, which ranked Canada 28th among 34 OECD countries (C3PR, 2013). To further aggravate the problem, the current physician pool as well as the general population in Canada are aging: forty-one percent of Canada's physicians were aged 55 or older in 2013 (C3PR, 2013). Additionally, the aging population of the country comprises Canadians



aged 65 and older who consume 45% of the total health care budget (Canadian Institute for Health Information, 2014). Due to shortage of new physicians, the existing physicians are burdened with the health issues of the aging population. These numbers suggest that there is a dire need to expand the physician population of Canada in order to combat the growing shortage in the workforce.

#### Discussion

Physician burnout in Canada is a problem that cannot be overcome easily. It not only reduces efficiency of the medical staff but also increases medical errors, thus reducing patient safety. The inability to physically withdraw from patients pushes physicians to psychologically withdraw from them, resulting in worsening health outcomes for the patients (Olson, 2017). Following this, there is an increase in recovery times, further increasing the wait time problem in Canada. Further, since many physicians have been leaving the profession or reducing their work hours, the loss of revenue from physicians has massively increased over the years (Martin, 2002). Over the years, the percentage of physicians accepting new patients has been dropping; it is becoming a hassle for patients to look for a general physician (CMA, 2017), and this reduces the quality of basic health service delivery in the country. Currently, a very small amount of research papers are available that focus on physician burnout specifically in Canada. This issue needs to be thoroughly investigated on a national level in order to devise further strategies and resolutions in the future.

### **Concluding Remarks**

The problem of physician burnout has existed for a long time globally, and its consequences have been impacting health care service delivery. It will require a great deal of effort and some major organizational changes to fight this epidemic of physician burnout. Removing the stigma that prevents physicians from discussing their stresses, implementing

strategies to reschedule long shifts, and reducing the number of patients per physician are some measures that can help in reducing physician fatigue. Organizational change will aid physicians in becoming more direct about seeking help and becoming less burdened (De Simone et al., 2019). It is also important to note that if the government does not take steps to increase medical infrastructure or, alternatively, increase the inflow of physicians, Canada will face a severe shortage of medical workers in the

### References

Boyle, T. (2018, October 10). Canadian doctors are suffering from burnout at an 'alarming' rate, survey finds. The Star. https://www.thestar.com/news/gta/2 018/10/10/md-burnout-an-alarmingproblem-cma-president-says.html

Canadian Collaborative Centre for Physician Resources. (2013). Canadian physician resources - 2013 basic facts.

Canadian Institute for Health Information. (2014). National health expenditure trends, 1975 to 2014. https://publications.gc.ca/collections/c ollection\_2015/icis-cihi/H118-2-2014eng.pdf

Canadian Medical Association. (2013). Physicians per 100,000 population by province/territory, Canada, 1986-2015. https://www.cma.ca/sites/default/files /pdf/Physician%20Data/12-Phys\_per\_pop.pdf

Canadian Medical Association. (2017). Average hours worked per week by physicians, 1997-2017.

> https://www.cma.ca/sites/default/files /pdf/Physician%20Data/34-

TrendData-e.pdf

Canadian Medical Association. (2018). CMA National Physician Health Survey: A national snapshot. https://www.cma.ca/sites/default/files /2018-11/nph-survey-e.pdf

Chan, B. T. B. (2002, June). From perceived surplus to perceived shortage: What



- happened to Canada's physician workforce in the 1990s? Canadian Institute for Health Information. https://secure.cihi.ca/free\_products/ch anjun02.pdf
- Chochinov, A., & Lim, R. (2020). *On the brink of burnout: COVID-19 and the ER.* Canadian Association of Emergency Physicians. https://caep.ca/wp-content/uploads/2020/03/CAEP-Wellness-OpEd\_Final\_Clean.pdf
- De Simone, S., Vargas, M., & Servillo, G. (2019). Organizational strategies to reduce physician burnout: A systematic review and meta-analysis. *Aging Clinical and Experimental Research*, 33(4), 883–894. https://doi.org/10.1007/s40520-019-01368-3
- Dewa, C. S., Jacobs, P., Thanh, N. X., & Loong, D. (2014). An estimate of the cost of burnout on early retirement and reduction in clinical hours of practicing physicians in Canada. *BMC Health Services Research*, 14, Article 254. https://doi.org/10.1186/1472-6963-14-254
- Dewa, C. S., Loong, D., Bonato, S., Thanh, N. X., & Jacobs, P. (2014). How does burnout affect physician productivity? A systematic literature review. *BMC Health Services Research*, 14, Article 325. https://doi.org/10.1186/1472-6963-14-325
- Dobbins, M. (2017, July 12). Rapid review guidebook: Steps for conducting a rapid review. National Collaborating Centre for Methods and Tools. https://www.nccmt.ca/uploads/media/media/0001/01/a816af720e4d587e1 3da6bb307df8c907a5dff9a.pdf
- Drummond, D. (2015). Physician burnout: Its origin, symptoms, and five main causes. *Family Practice Management, 22*(5), 42–47. https://www.aafp.org/fpm/2015/0900/p42.html
- Dyrbye, L. N., Thomas, M. R., Massie, F. S., Power, D. V., Eacker, A., Harper, W., Durning, S., Moutier, C., Szydlo, D. W.,

- Novotny, P. J., Sloan, J. A., & Shanafelt, T. D. (2008). Burnout and suicidal ideation among U.S. medical students. *Annals of Internal Medicine*, *149*(5), 334–341. https://doi.org/10.7326/0003-4819-149-5-200809020-00008
- Garland, A., Roberts, D., & Graff, L. (2012).

  Twenty-four-hour intensivist presence:
  A pilot study of effects on intensive care unit patients, families, doctors, and nurses. American Journal of Respiratory and Critical Care Medicine, 185(7), 738–743.

  https://doi.org/10.1164/rccm.201109-
  - 17340C
- Gulati, G., & Kelly, B. D. (2020). Physician suicide and the COVID-19 pandemic. *Occupational Medicine, 70*(7), 514. https://doi.org/10.1093/occmed/kgaa104
- Ireland, S. (2021, April 27). Revealed: Countries with the best health care systems, 2021. *CEOWORLD Magazine*. https://ceoworld.biz/2021/04/27/rev ealed-countries-with-the-best-health-care-systems-2021/
- Ivan, I. (n.d.). Post graduation pathways in the UK for IMGs. *Road to UK*. https://www.roadtouk.com/postgraduation/postgraduation-pathways/
- Kuhn, C.M., & Flanagan, E.M. (2017). Self-care as a professional imperative: Physician burnout, depression, and suicide. *Canadian Journal of Anesthesia*, *64*, 158–168. https://doi.org/10.1007/s12630-016-0781-0
- Linzer, M., Poplau, S., Grossman, E., Varkey, A., Yale, S., Williams, E., Hicks, L., Brown, R. L., Wallock, J., Kohnhorst, D., & Barbouche, M. (2015). A cluster randomized trial of interventions to improve work conditions and clinician burnout in primary care: Results from the Healthy Workplace (HWP) Study. *Journal of General Internal Medicine*, 30(8), 1105–1111. https://doi.org/10.1007/s11606-015-3235-4



- Malko, A. V., & Huckfeldt, V. (2017). Physician shortage in Canada: A review of contributing factors. *Global Journal of Health Science*, 9(9), 68–80. https://doi.org/10.5539/gjhs.v9n9p68
- Martin, S. (2002). More hours, more tired, more to do: Results from the CMA's 2002 Physician Resource Questionnaire. *CMAJ: Canadian Medical Association Journal*, 167(5), 521–522. https://www.cmaj.ca/content/167/5/521.1
- Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. *Journal of Organizational Behavior, 2*(2), 99–113. https://doi.org/10.1002/job.40300202 05
- Medical Council of Canada. (n.d.). *Medical Council of Canada Qualifying Examination Part I*.

  https://mcc.ca/examinations/mccqepart-i/
- Olson, K. D. (2017). Physician burnout—A leading indicator of health system performance? *Mayo Clinic Proceedings*, 92(11), 1608–1611. https://doi.org/10.1016/j.mayocp.2017.09.008
- Panagioti, M., Panagopoulou, E., Bower, P.,
  Lewith, G., Kontopantelis, E., ChewGraham, C., Dawson, S., van Marwijk, H.,
  Geraghty, K., & Esmail, A. (2017).
  Controlled interventions to reduce
  burnout in physicians: A systemic
  review and meta-analysis. *JAMA Internal Medicine*, 177(2), 195–205.
  https://doi.org/10.1001/jamainternme
  d.2016.7674
- Parker, J., & Mirzaali, M. (2020, March 16). The moral cost of coronavirus. *Journal of Medical Ethics Blog*. https://blogs.bmj.com/medicalethics/2020/03/16/the-moral-cost-of-coronavirus/
- Ruitenburg, M. M., Frings-Dresen, M. H. W. & Sluiter, J. K. (2012). The prevalence of common mental disorders among hospital physicians and their

- association with self-reported work ability: A cross-sectional study. *BMC Health Services Research*, *12*, Article 292. https://doi.org/10.1186/1472-6963-12-292
- Salyers, M. P., Bonfils, K. A., Luther, L., Firmin, R. L., White, D. A., Adams, E. L., & Rollins, A. L. (2017). The relationship between professional burnout and quality and safety in healthcare: A meta-analysis. *Journal of General Internal Medicine* 32(4), 475–482. https://doi.org/10.1007/s11606-016-3886-9
- Shanafelt, T. D., Lightner, D. J., Conley, C. R., Petrou, S. P., Richardson, J. W., Schroeder, P. J., Brown, W. A. (2017). An organizational model to assist individual physicians, scientists, and senior health care administrators with personal and professional needs. *Mayo Clinic Proceedings*, *92*(11), 1688–1696. https://doi.org/10.1016/j.mayocp.2017.08.020
- Shea, J. A., Bellini, L. M., Dinges, D. F., Curtis, M. L., Tao, Y., Zhu, J., Small, D. S., Basner, M., Norton, L., Novak, C., Dine, J., Rosen, I. M., & Volpp, K. G. (2014). Impact of protected sleep period for internal medicine interns on overnight call on depression, burnout, and empathy. *Journal of Graduate Medical Education*, 6(2), 256–263. https://doi.org/10.4300/JGME-D-13-00241.1
- Sinsky, C. A., Dyrbye, L. N., West, C. P., Satele, D., Tutty, M., & Shanafelt, T. D. (2017). Professional satisfaction and the career plans of US physicians. *Mayo Clinic Proceedings*, 92(11), 1625–1635. https://doi.org/10.1016/j.mayocp.2017.08.017
- Siu, C. F. Y., Yuen, S. K., & Cheung, A. (2012).

  Burnout among public doctors in Hong
  Kong: Cross-sectional survey. *Hong Kong Medical Journal, 18*(3), 186–192.

  https://www.hkmj.org/abstracts/v18n
  3/186.htm



- Slade, S. (2014). *IMGs in Canada: Data and the changing gestalt* [PowerPoint slides]. Royal College of Physicians and Surgeons of Canada. https://www.royalcollege.ca/rcsite/documents/health-policy/imgs-in-canadafeb-2014-steve-slade.pdf
- Soler, J. K., Yaman, H., Esteva, M., Dobbs, F.,
  Asenova, R. S., Katic, M., Ozvacic, Z.,
  Desgranges, J. P., Moreau, A., Lionis, C.,
  Kotanyi, P., Carelli, F., Nowak, P. R., de
  Aguiar Sa Azeredo, Z., Marklund, E.,
  Churchill, D., Ungan, M., & European
  General Practice Research Network
  Burnout Study Group. (2008). Burnout
  in European family doctors: The EGPRN
  study. Family Practice, 25(4), 245–265.
  https://doi.org/10.1093/fampra/cmn0
  38
- The Canadian Medical Protective Association. (2018a). Healthier physicians: An investment in safe medical care. https://www.cmpa-acpm.ca/static-assets/pdf/about/annual-meeting/18\_healthier\_physicians\_backg rounder-e.pdf
- The Canadian Medical Protective Association.

  (2018b, August 22). Canadian Medical
  Protective Association calls for systemwide change to improve physician
  wellness [Press release].
  https://www.cmpaacpm.ca/en/connect/mediaroom/2018/canadian-medicalprotective-association-calls-for-systemwide-change-to-improve-physicianwellness
- Vo, E. (2019, August 30). Why do you discount cash flows? *The Hartford*. https://sba.thehartford.com/finance/cash-flow/discounting-cash-flows/
- World Health Organization. (2010). Monitoring the building blocks of health systems: A handbook of indicators and their measurement strategies.

  https://www.who.int/workforcealliance/knowledge/toolkit/26/en/



### Research Article

# Optional or Obligatory? Exploring Undergraduate University Students' Attitudes, Opinions, and Beliefs Around Verbal Sexual Consent

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#### **Abstract**

**Introduction:** For the last 20 years, sexual assault on university campuses has occurred at epidemic levels. This may be caused by undergraduate students primarily using non-verbal cues to communicate sexual consent, despite high levels of miscommunication and misinterpretation. Explicit, verbalized consent is known to lead to fewer misinterpretations of consent; however, less is known about students' beliefs around verbal consent. Objectives: To explore Canadian undergraduate students' attitudes, opinions, and beliefs around verbal consent, and to investigate whether students believe verbal consent is always required during sexual encounters. **Methods**: This study used a qualitative description approach. Data was collected from 31 Canadian undergraduate students in a Human Sexuality course through an open-ended question embedded in an interactive course textbook. Students' responses were analyzed using thematic analysis. Results: Many complexities exist in undergraduate students' attitudes, opinions, and beliefs around verbal consent. Four major themes emerged from the data centring on familiarity, socio-cultural norms, reliance on non-verbal cues, and acknowledgement of the importance of verbal consent. Conclusion: The majority of participants believed that verbal consent was not required in all sexual encounters. Partner familiarity was a significant factor in using verbal consent. Social norms such as verbal consent being viewed as awkward or embarrassing were key barriers to students' use. Verbal consent was viewed as an ideal, while non-verbal consent was viewed as realistic.



Optional or Obligatory? Exploring Undergraduate University Students' Attitudes, Opinions, and Beliefs Around Verbal Sexual Consent

University campuses have been identified as one of the most prevalent settings where sexual assault (SA) occurs (Quinlan et al., 2016). The Criminal Code (1985, c. C-46, s. 271.1 [1]) describes SA as "an assault committed in circumstances of a sexual nature such that the sexual integrity of the victim is violated." SA occurs when sexual consent is lacking in sexual encounters. According to the Criminal Code of Canada (1985, c. C-46, s. 273.1 [1]), sexual consent is defined as "the voluntary agreement to engage in the sexual activity in question." University students are significantly more likely to experience SA compared to the general population (Marcantonio et al., 2018; Pugh & Becker, 2018; Senn et al., 2014). Research has found that one in four women enrolled in a North American university will experience some form of sexualized violence (Senn et al., 2014). SA is rooted in gender inequality and is a persistent form of gender-based violence that marginalize, continues to harm, disempower women in society (World Health Organization, 2012). Achieving gender equality is one of the United Nations' sustainable development goals (United Nations, n.d.). However, rates of SA on university campuses remain at epidemic levels (Potter et al., 2018; Senn et al., 2014).

University campuses perpetuate an environment that is conducive to SA due to complex socio-cultural norms, including high levels of hypermasculine norms, high levels of rape myth acceptance, and reliance on nonverbal consent (Jozowski et al., 2014). SA is inextricably linked to consent, as sexual consent is the differentiating factor between consensual and non-consensual sexual activity (Jozkowski & Peterson, 2013). Universities have begun emphasizing explicit verbal consent as the standard for obtaining sexual consent (Curtis & Burnett, 2017). The need for verbal consent has been highlighted in prior research showing that non-verbal consent contributes to high rates of

SA (Hermann et al., 2018). Despite this, virtually no research to date has been conducted specifically examining undergraduate (UG) students' beliefs around verbal consent. Additionally, most of the research on sexual consent has been focused on American students, causing the experiences of Canadian students to be less well understood. This is concerning, as Canadian students are believed to be more at risk of experiencing SA than American students (Daigle et al., 2019). To address the gaps in the literature, the purpose of this study was to explore the attitudes, opinions, and beliefs around verbal consent among Canadian UG students. The purpose of this study was addressed through the following research questions:

- a) What are the current attitudes, opinions, and beliefs of undergraduate students enrolled in a Canadian university around verbal consent?
- **b)** To what extent do undergraduate students enrolled in a Canadian university believe verbal consent *always* needs to be used during sexual encounters?

### Methods

Qualitative research attempts to "make sense of or interpret the phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, 2011, p. 3). This approach was chosen to provide an in-depth exploration of UG students' beliefs around verbal consent, as qualitative methodologies allow rich descriptions of beliefs, values, and practices to be captured (Denzin & Lincoln, 2011).

Qualitative research is steeped in core philosophical beliefs: Ontological, epistemological, axiological and beliefs (Creswell & Poth, 2018). These elements were considered throughout this study. Ontological beliefs relate to the nature of reality and embracing multiple realities (Creswell & Poth, 2018). Ontological beliefs were supported through the qualitative description design, as this allowed me to stay true to participants' words without high levels of interpretation, demonstrating the multiple perceptions held by



participants. Epistemological beliefs focus on conducting the study in the field to understand participant context (Creswell & Poth, 2018). **Epistemological** beliefs encourage researcher to "minimize the distance between himself or herself and those being researched" (Creswell & Poth, 2018, p. 21). This was achieved through my positionality in the research. I recently graduated from my UG program and am now a graduate student. I have first-hand knowledge of the socio-cultural complexities that exist on university campuses surrounding sexual consent. Finally, axiological beliefs centre around the researcher bringing their existing biases and values to the forefront and positioning themselves in their research based on social position and personal experiences (Creswell & Poth, 2018). As a White, cisgender, heterosexual woman pursuing higher education, I recognize that my privilege and lived experience will influence how I interpreted the data. While this is acknowledged, it is not a limitation of the study, as qualitative research recognizes that the researcher's presence is inherent in the text just as much as the subject of study (Creswell & Poth, 2018).

### **Study Design**

Qualitative description was used for this study. Qualitative description provides insight on a topic that has not been previously studied by describing the phenomenon in the language used by the participants (Neergaard et al., 2009; Sandelowski, 2000). There has been virtually no research conducted examining verbal consent specifically, making qualitative description an ideal fit.

### **Original Study and Participants**

This study used previously generated data that had been collected from a larger project but had not yet been analyzed. The original project, titled *Educational Technology* and Research Design: An exploratory mixed-methods study on predictors of undergraduate students' attitudes, opinions and beliefs on sexuality, was led by Dr. Matthew Numer and explored UG students' attitudes, opinions, beliefs, and practices around sex, gender, and

sexuality. In the larger project, data was collected from UG students attending two similar-sized universities, one located in Canada and one located in the United States, enrolled in similar Human Sexuality courses; Data was collected using a mixed-method approach, employing two survey instruments and six open-ended questions requiring student's written responses. My study analyzed UG students' written responses to one of the openended questions: Do you believe sexual consent should always require verbal consent? Why/why not? Only Canadian data were used for this study, due to time constraints and capacity. The original study was provided with ethical approval by the Dalhousie Research Ethics Board. I submitted an amendment to the existing ethics to conduct this study for the fulfillment of the Bachelor of Science (Health Promotion) Honours degree program. Data used in this study was not included in the results of the original study.

### Recruitment, Data Collection and Data Analysis

Recruitment for this study took place during the original project. Only the Canadian UG students recruited were included in this study. Students were enrolled and recruited from a Human Sexuality course. Data was collected using the required interactive course textbook, embedded into Top Hat. Top Hat is a web-based interactive education platform that offers instructors the ability to engage with their students electronically through classroom activities, course assignments, tests, and digital textbooks (Top Hat, n.d.). The open-ended questions were part of the course load for the class, so students were required to answer them; however, students were not obligated to have their responses used as part of the study. Thirty-one students consented to responses being used for research purposes. Student responses to the one open-ended question were analyzed following the six-step process to thematic analysis outlined by Braun & Clarke (2006).



### **Results**

Thematic analysis revealed four main themes on UG students' beliefs around verbal consent: Partner Familiarity, Social Norms, You Just Know, and Verbal is Ideal. I will describe each theme below and provide direct quotes from student's responses to provide justification.

### **Partner Familiarity**

One of the most prevalent beliefs held by participants was that partner familiarity influenced verbal consent practices. Students repeatedly explained that verbal consent should be used if partners are not familiar with each other, such as in a new relationship or during first-time sexual encounters. One participant stated that "Verbal consent is important in newer relationships to lay out the mutual feelings of the partners." Similarly, one student explained that "If the relationship is new and the people involved aren't quite sure of the other person, verbal consent is something very important to establish." Students felt that verbal consent was crucial in new relationships to build trust between partners, as one student explained: "Sexual consent should be given in all first encounters and continued in early relationships until a trust is built between the partners and they can trust that what they are doing is accepted by the other."

Students also held the opinion that, in a relationship, partners should feel comfortable telling their partner no if they do not want to have sex, suggesting that consent was established based on the absence of no. One participant wrote that "If they do not want to have sex, they should feel comfortable enough in a long-term relationship to say so."

Participants explained that if two individuals are in a long-term, exclusive relationship, verbal consent is not always required. One participant commented:

You become familiar with your sexual partner when having been in a long term relationship and when it's not your first sexual encounter with that person. You become very aware of their body language, the things they enjoy or do not

enjoy, and it becomes easily apparent whether they consent even if they don't verbally tell you.

Students also felt that in a long-term relationship there was an understanding of ongoing consent, causing students to believe that verbal consent was not required. For example, one participant wrote that "If you have an established sexual relationship with someone then I think there is the idea of an existing basis of consent to certain sexual activities."

### **Social Norms**

Verbal consent was perceived as something that did not contribute to a comfortable sexual encounter. A barrier to using verbal consent was that it was perceived as awkward or uncomfortable, with one student commenting:

"I do not believe that sexual consent should always require verbal consent because it can ruin as moment." Another student stated that "it can be awkward for someone to be verbal when consenting but you can usually tell if they are okay or not okay with what is happening by nonverbal cues."

This quote demonstrates that students rely on non-verbal cues instead of verbal consent in an attempt to avoid social repercussions associated with using verbal consent.

Many students struggled with a negative perception of verbal consent because they felt that it was not perceived as attractive. Despite this, UG students also acknowledged the importance of verbal consent, which is exemplified by one student who wrote "I am torn on this as I believe [verbal consent] kills the mood but is also very important." Similarly, another student stated that "it is an unfortunate fact that not everyone finds [verbal consent] attractive." These quotes highlight that UG students acknowledge the importance of verbal consent, yet struggle with the social scripts of what is considered attractive and appropriate in sexual encounters.

Several students described attempting to combat the current negative perceptions of verbal consent by using alternative phrasing.



For example, one student explained that "I don't think I've ever received a straight up 'yes' or 'no' from anyone regarding sex ... it's important to truly watch the other person ... how their body reacts ... a 'just like that' or a 'keep going'." This quote demonstrates that while students seek verbal reassurance of consent, they do not obtain verbal consent prior to sexual acts and instead rely on non-verbal cues. Many participants felt that using alternative phrasing when verbally asking for consent from their partner was more realistic and easier to achieve. One participant stated that "Sexual consent should always require some verbal element such as one person asking, 'do you want to?' or 'okay?'" This belief was shared by another student, who wrote "We all have certain behaviours that indicate we are interested in sexual acts, but I still [feel] that before starting a simple 'are you okay with this?' is not too hard." This quote demonstrates that UG students believe that using alternative phrasing makes verbal consent more accessible and easier to apply during sexual encounters. Similarly, another student stated the following:

Giving verbal cues may not seem like the most natural or easiest thing to do in such an intimate setting, but if both people verbally say they want to engage in a certain sexual act, then it is clear that both people are consenting and they both want to.

This student acknowledged that verbal consent is viewed negatively; however, this student also holds the belief that verbal consent ensures sexual activity is consensual, thus enhancing the experience of all partners. Despite this, the majority of UG students felt that obtaining consent via non-verbal cues was sufficient.

### "You Just Know"

Verbal consent is typically lacking during UG students' sexual encounters. The primary method of obtaining sexual consent among UG students was non-verbal cues. Participants felt that verbal consent was not always required in sexual encounters, as many believed that a partner's non-verbal cues were

sufficient in determining consent. As one student wrote:

"There is a clear difference between someone who is positively responding to sexual activity (making sounds, touching back, kissing back, moving with pleasure when being touched), compared with someone who has stiffened, stopped responding, etc."

Another participant shared a similar view, stating "There is a major difference between willing and resisting." Students emphasized examining body language and partner reciprocation to determine a partner's consent: "There are many other ways besides verbally to give your consent such as through smiling, nodding, or reciprocating the actions to your partner."

Students also wrote that they relied on non-verbal cues to determine if their partner was not comfortable: "You can usually tell if they are okay or not okay with what is happening by non-verbal cues such as trying to stop the other person or looking upset."

While the majority of participants felt that non-verbal cues provided a sufficient basis of consent, one UG student acknowledged the importance of being comfortable communicating concerns to their partner:

"I think that sexual consent does not always have to be verbal but it is important that individuals should be comfortable enough to verbally communicate if something is wrong."

While students felt that there were instances where verbal consent should be used, the majority of participants felt that non-verbal cues were sufficient in determining consent.

### Verbal is "Ideal"

Students believed that they were expected to use verbal consent but did not seem to integrate it into their sexual encounters. One participant stated "I believe that in some cases verbal consent may not be needed. I say this with caution as most times verbal consent should be given." Another student wrote, "it is evident by body language when individuals are or aren't into



it, yet there is no harm in verifying by asking your partner if they want to."

While the majority of students relied on non-verbal consent, several students fully endorsed the benefits of verbal consent and indicated that they believed it should be integrated into all sexual encounters. According to one participant, "I think verbal consent is the best way to give consent because I think communication is key. Even indirect verbal communication can lead to miscommunication in any situation so with regards to sex [verbal consent] is extremely important."

Similarly, another participant felt that using verbal consent in all sexual encounters ensures that both partners approve of what is happening and that the sexual activity is consensual. For example, one participant wrote the following:

Many people would take nonverbal cues to mean that consent has been given ... however this could lead to miscommunication, and possibly sexual activity where one party believes consent was given and the other does not. I think, in order to be safe and make sure both parties are fully engaged, verbal consent should always be given just to make sure that all parties engaging in the activity are on the same page.

### **Discussion**

The purpose of this study was to explore UG students' attitudes, opinions, and beliefs around verbal consent. The findings highlight barriers to UG students integrating verbal consent into their sexual encounters and into the social norms that prevail on university campuses around sexual consent. There was a clear emphasis placed on relationship status, partner familiarity and use of verbal consent. This finding has been supported in prior research, showing that university students typically use verbal consent during first-time sexual encounters due to lack of familiarity but rely on non-verbal cues in long-term relationships (Marcantonio et al., 2018; Curtis & Burnett, 2017). This remains concerning because 50% of reported cases of SA are

perpetrated by someone known to the victim (Government of Canada, 2019).

Current perceptions of verbal consent among UG students show that verbal consent is considered awkward and uncomfortable. Prior research has demonstrated similar findings, showing that UG students avoid verbal consent due to the perceived embarrassment of both request and refusal (Curtis & Burnett, 2017). Participants in this study stated that while these social norms persist, incorporating verbal consent more naturally by using alternative phrasing is a technique to combat the stigma. The negative perception of verbal consent is supported by both the media and peers, causing peers to often ridicule those who explicitly ask for verbal consent (Curtis & Burnett, 2017). The findings of this study can support this concept, as the majority of participants stated that they did not believe verbal consent was required in all sexual encounters. Students believed that partners should be able to determine if a partner was willing or resisting sexual activity based solely on their physical cues. This finding supports other research that has found that UG students typically rely on non-verbal cues due to the common belief that "you just know" when a partner is consenting (Curtis & Burnett, 2017). Despite this, many students understood the benefits of verbal consent and stated that verbal consent caused fewer misinterpretations: however, these beliefs were often contradicted by students' beliefs that a partner's physical cues would clearly indicate their consent.

### **Conclusion & Recommendations**

The findings of this study show that UG students view the need for verbal consent as contextual, based on a number of factors. A key takeaway from this study was that UG students' beliefs and practices around verbal consent may contradict each other due to social norms and pressures. The current social environment on university campuses surrounding verbal consent is harming the health of UG students by contributing to the unrelenting rates of SA. Based on the findings of this study, it is clear that the current stigma and social perception of



verbal consent needs to be considered when addressing SA on university campuses. Campus interventions should be created to shift perceptions of verbal consent in a way that is meaningful and relevant to this population. Examples may include social media campaigns that promote verbal consent or student-led initiatives that start conversations around verbal consent.

### **Implications & Future Research**

The findings of this research contribute to two core competencies of the Healthy Populations Institute: Agents of change and research, policy, and practice (Miller et al., 2021). These findings can be used to shift universities' socio-cultural environments to reduce institutionalized support of SA. The findings could also help strengthen campus policies and practices around sexual consent to combat the SA epidemic.

Future research should consider whether characteristics such as gender, sexual orientation, age, or discipline influence UG students' beliefs around verbal consent. Further, a similar study using discourse analysis should be conducted to examine the interactions between beliefs, practices, social position, and relations of power.

### References

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706q p0630a
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative* inquiry and research design: Choosing among five approaches (4th ed.). Sage Publications.
- Criminal Code, RSC 1985, c. C-46, s. 271.1 (1). Criminal Code, RSC 1985, c. C-46, s. 273.1 (1).
- Curtis, J. N., & Burnett, S. (2017). Affirmative consent: What do college student leaders think about "yes means yes" as the standard for sexual behavior? *American Journal of Sexuality*

- Education, 12(3), 201–214. https://doi.org/10.1080/15546128.20 17.1328322
- Daigle, L. E., Johnston, T., Azimi, A., & Felix, S. N. (2019). Violent and sexual victimization among American and Canadian college students: Who is more at risk and are the risk factors invariant? *Journal of School Violence*, 18(2), 226–240. https://doi.org/10.1080/15388220.20 18.1459631
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The Sage handbook of qualitative research* (4<sup>th</sup> ed.). Sage.
- Government of Canada (2019). JustFacts: Sexual assault. *Department of Justice*. https://www.justice.gc.ca/eng/rp-pr/jr/jf-pf/2019/apr01.html
- Gray, J. M. (2015). What constitutes a "reasonable belief" in consent to sex? A thematic analysis. *Journal of Sexual Aggression*, *21*(3), 337–353. https://doi.org/10.1080/13552600.20 14.900122
- Hermann, C., Liang, C. T. H., & DeSipio, B. E. (2018). Exploring sexual consent and hostile masculine norms using the theory of planned behavior. *Psychology Of Men & Masculinity*, 19(4), 491–499. https://psycnet.apa.org/doi/10.1037/men0000127
- Jozkowski, K. N., Manning, J., & Hunt, M. (2018). Sexual consent in and out of the bedroom: Disjunctive views of heterosexual college students. *Women's Studies in Communication*, 41(2), 117–139.
  - https://doi.org/10.1080/07491409.20 18.1470121
- Jozkowski, K. N., & Peterson, Z. D. (2013). College students and sexual consent: Unique insights. *Journal of Sex Research*, *50*(6), 517–523. https://doi.org/10.1080/00224499.20 12.700739
- Jozkowski, K. N., Peterson, Z. D., Sanders, S. A., Dennis, B., & Reece, M. (2014). Gender differences in heterosexual college students' conceptualizations and



- indicators of sexual consent: Implications for contemporary sexual assault prevention education. *The Journal of Sex Research*, *51*(8), 904–916. https://doi.org/10.1080/00224499.20 13.792326
- Marcantonio, T., Jozkowski, K. N., & Wiersma-Mosley, J. (2018). The influence of partner status and sexual behavior on college women's consent communication and feelings. *Journal of Sex & Marital Therapy*, 44(8), 776–786. https://doi.org/10.1080/0092623X.20 18.1474410
- Marcantonio, T. L., Jozkowski, K. N., & Lo, W.-J. (2018). Beyond "Just saying no": A preliminary evaluation of strategies college students use to refuse sexual activity. *Archives Of Sexual Behavior*, 47(2), 341–351. https://doi.org/10.1007/s10508-017-1130-2
- Miller, L., Brushett, S., Ayn, C., Furlotte, K., Jackson, L., MacQuarrie, M., Massie, A. S., Mathias, H., McKay, M., Meisner, B. A., Moritz, L., Stilwell, C., & Weeks, L. E. (2021). Developing a competency framework for population health graduate students through student and faculty collaboration. *Pedagogy in Health Promotion*, 7(3), 280–288. https://doi.org/10.1177%2F23733799 19859607
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description the poor cousin of health research? *BMC Medical Research Methodology*, 9, Article 52. https://doi.org/10.1186/1471-2288-9-52
- Potter, S., Howard, R., Murphy, S., & Moynihan, M. M. (2018). Long-term impacts of college sexual assaults on women survivors' educational and career attainments. *Journal of American College Health*, 66(6), 496–507. https://doi.org/10.1080/07448481.20 18.1440574

- Pugh, B., & Becker, P. (2018). Exploring definitions and prevalence of verbal sexual coercion and its relationship to consent to unwanted sex: Implications for affirmative consent standards on college campuses. *Behavioral Sciences*, 8(8), Article 69. https://doi.org/10.3390/bs8080069
- Quinlan, E., Clarke, A., & Miller, N. (2016).
  Enhancing care and advocacy for sexual assault survivors on Canadian campuses. *Canadian Journal of Higher Education*, 46(2), 40–54.
  https://doi.org/10.47678/cjhe.v46i2.185184
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340. https://doi.org/10.1002/1098-240X(200008)23:4%3C334::AID-NUR9%3E3.0.CO;2-G
- Senn, C. Y., Eliasziw, M., Barata, P. C., Thurston, W. E., Newby-Clark, I. R., Radtke, H. L., Hobden, K. L., & SARE Study Team (2014). Sexual violence in the lives of first-year university women in Canada: No improvements in the 21st century. *BMC Women's Health*, 14, Article 135. https://doi.org/10.1186/s12905-014-0135-4
- Top Hat (n.d.). Top Hat Classroom. https://tophat.com/classroom/
- United Nations (n.d.). Goal 5: Achieve gender equality and empower all women and girls.
  - https://www.un.org/sustainabledevelopment/gender-equality/
- World Health Organization (2012).

  Understanding and addressing violence
  against women: Sexual Violence.
  https://apps.who.int/iris/bitstream/ha
  ndle/10665/77434/WHO\_RHR\_12.37\_e
  ng.pdf;jsessionid=1B7DA2157511B30D
  07141C4561F4B03E?sequence=1



### Research Article

## Conduct Disorder: A Review of the Literature and the Impact on Caregivers

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#### **Abstract**

**Introduction**: Conduct disorder (CD) is a problematic psychiatric disorder that presents significant challenges for caregivers and families. CD itself has an abundance of literature, although minimal focus has been given toward caregiver mental health and overall well-being. **Objectives:** This paper reviewed the literature on the burden of caring for youth with CD on caregivers' mental health. Specifically, we (a) briefly synthesized the existing knowledge on the impact of CD on caregivers while pointing to gaps in literature, and (b) provided recommendations to clinicians caring for youth with CD and their families. Methods: Using specific inclusion/exclusion criteria, we located published studies from 2000-2020 on CD and caregivers' mental health from PsycInfo and PubMed. Results: The four articles that met inclusion criteria for this review utilized different scales and interview techniques to measure caregiver strain, making quantitative comparisons challenging. However, three prevalent reoccurring themes were present among these articles: an increase in caregiver negative emotional states, poor parent-child relationships, and adverse effects on caregivers' spousal relations while caring for a youth with CD. Conclusion/Discussion: This literature review noted the paucity of empirical research on CD and caregiver strain. Our findings reiterate the negative impact this disorder has on caregivers' mental health, child-parent relationships, and spousal relations. CD is responsible for substantial societal costs due to criminality and special education arrangements; however, many secondary issues of CD may be offset through access to parenting programs such as Triple P and proper access to clinical support teams.



### Conduct Disorder: A Review of the Literature and the Impact on Caregivers

Conduct disorder (CD), primarily characterized by aggression toward people and animals, property destruction, theft, and serious rule violations, is a problematic psychiatric disorder that generates significant impairment of daily functioning (American Psychiatric Association, 2013). The worldwide prevalence of CD in children and adolescents is an estimated 2.1% according to data pooled from 41 studies (Polanczyk et al., 2015). Nearly two-thirds of parents of youth with CD report feeling depressed, while a notable group of 30.9% report seeing a doctor due to difficulty coping with their child's disorder (Meltzer et al., 2011). Most of the early and recent research on CD has focused almost exclusively on the diagnosed youth, omitting caregivers (Manor-Binyamini, 2012). Specifically, epidemiological studies are limited, and the majority of these are not focused on caregivers (Meltzer et al., 2011). This review of the literature addressed this gap by focusing on caregivers, which we defined as an unpaid individual who cares for a youth with CD. Extrapolating from findings on other psychiatric conditions, such as mothers caring for an adolescent with depression (Armitage et al., 2020), studying caregivers' strain is crucial to improve not only their lives but those of the entire family.

Over the past decades, research has shown that multiple factors may contribute to the behavioural symptoms of CD (Pardini & Frick, 2013). If researchers develop a more rigorous etiological understanding of CD, it may refining future treatments interventions (Salvatore & Dick, 2018). A literature review by Salvatore and Dick (2018) compiled results from five studies with an estimated 32,815 twins from the USA, Sweden, and Australia. Their review found a modest to moderate influence of a genetic contribution for CD. A genetic contribution, of course, generates a higher disposition for CD, although it does not guarantee an outcome (Salvatore & Dick, 2018). The authors point out that even though individuals may have high predispositions to the

disorder, some may never develop CD. As highlighted in Salvatore and Dick's (2018) review, it was found that both parent-child conflict (Burt & Klump, 2014) and parental struggle with drug dependency (Haber et al., 2010) contributed to the presence of CD phenotypes. The impact on caregivers raising a child or youth with CD can be significantly detrimental to both their physical and psychological well-being (Meltzer et al., 2011). Caregivers and families must navigate potential psychosocial harms, such as conflict, spousal problems and feelings of helplessness, all the while attempting to care for their child/youth with CD and other children (Sajadi et al., 2020).

### **Objectives**

Building on the above findings and gaps in the published studies, our paper examined the current literature on CD and caregiver strain; more specifically, we investigated the impact that caring for a youth diagnosed with CD has on a caregiver's overall well-being and health. Our review is necessary to shed light on caregivers' challenges in managing a youth's CD behaviours, in addition to providing an overview of societal costs (e.g., school dropout, licit or illicit drug use, violence, familial conflicts, law breaking, and risk for out-of-home placements, including foster care, residential services, or even the juvenile justice system). It was predicted that caregiver strain, psychological well-being, and familial stress will all be negatively affected while caring for a CD youth.

### Methods

We conducted a literature review on the impact of caring for youth with CD on caregivers' mental health. We performed a title and abstract search on PsycInfo and PubMed using the following keywords: conduct disorder, conduct disorders, conduct disordered; caregiver, caregivers, care givers, carers, parent, parents, parental, mother, mothers, father, fathers; and burden, stress, fatigue, burnout, strain, impact, effect, effects, affect, affects, challenge, challenges. Inclusion



criteria consisted of the following: (a) empirical studies analyzing CD's emotional impact on caregivers, (b) articles published between 2000-2020, and (c) articles published in English. Exclusion criteria included following: (a) studies analyzing caregiver strain reduction after the implementation of a parent training program or a pharmacological treatment, and (b) studies incorporating participants with CD symptomatology without an official diagnosis. Article titles and abstracts were individually reviewed for keywords and related material. Figure 1 illustrates the selection process used throughout this review.

After the first co-author (RD) performed a title and abstract review of all articles, 17 were selected for a full text review by both RD and RA.

Thirteen of these articles were excluded for one of three reasons: (a) not focusing on CD, (b) youth lacking an official diagnosis, or (c) lacking a focus on caregiver strain. In total, four articles were included in this review.

#### Results

Each study analyzed caregiver strain using different methods; therefore, comparison is challenging. As shown in Table 1, the included

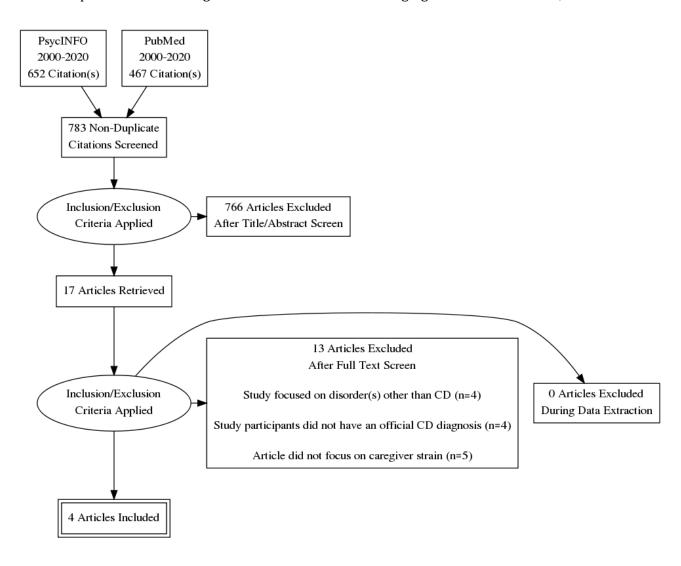


Figure 1
PRISMA Flowchart of Article Selection



**Table 1**Compiled Studies Analyzing Caregiver Burden of Caring for Youth/Children with Conduct Disorder (CD)

Study	Design	Sample	Assessments	Results	Limitations
Chaudhury et al. (2020) India	Cross- sectional, hospital based comparative study	120 parents; 60 parents (30 mothers and 30 fathers) of children (8-16 years of age) with CD/ODD, 60 parents of unaffected children (8-16 years of age)	C3-P; GHQ- 12; KSESS; PRQ; MQS	Parent-child relationship: Parents in the CD/ODD group reported lower levels of attachment, involvement, and parenting confidence. Parents of the study group also reported significantly higher levels of relational frustration Spousal quality: Parents in the CD/ODD group reported poorer marital quality.	Diagnoses: This study incorporates children diagnosed with both CD/ODD
Manor- Binyamini (2012) Israel	Cross sectional comparison study	400 parental couples; 300 parents of children (6-18 years of age) with CD, and 100 parents of children without CD)	CSI; SOC Index	Caregiver burden: Parents of youth with CD reported significantly higher levels of caregiver strain Sense of coherence: Parents of youth with CD reported significantly lower sense of coherence levels	Generalizability: 33% of youth diagnosed with CD had comorbid attention deficit hyperactivity disorder
Meltzer et al. (2011) United Kingdom	Secondary analysis of a (British) national survey data set	10,438 children (5-15 years of age) a part of a nationally representative survey	DAWBA; CABA	Caregiver burden: Compared to the emotional disorder group, CD generated higher levels of caregiver burden in many areas:  • Child with CD generated psychological illness in parents to some (18.2%) or to a great (9.9%) extent (n = 312)  • Coping difficulties leading to medical consultation (30.9%; n = 297)  • Increased smoking (if participants smoked; 49.3%; n = 224)	Sampling bias: Individuals who did not participate or could not be contacted (around 25% of sampled households) may have experienced more burden compared to active participants
Sajadi et al. (2020) Iran	Qualitative study (conducted from January 2019 – January 2020)	participants; children (8-12 years of age) with CD (n=5), their parents (n=6), teachers (n = 5), and social workers and psychology experts (n = 7)	Interviews - Directed content analysis	Caregiver burden: Five themes related to parental strain emerged from the data:  Marital problems  Feelings of helplessness and an inability to improve the conditions  Inappropriate discipline behaviours  Parents' lack of interest in obtaining treatment for their troubled child  Psychosocial harms of the family members	<b>Generalizability:</b> Some participants had comorbid disorders

studies noted the impact CD has on caregivers' psychological well-being, caregivers' relationships, and caregiver-child relations. In total, three of the studies selected were cross-sectional, two of which analyzed caregiver strain while raising a child/youth with CD in comparison to families of children without the disorder (Chaudhury et al., 2020; Manor-Binyamini, 2012). In addition to parents, the

final cross-sectional study incorporated the views of children with CD, teachers, and clinicians (Sajadi et al., 2020). One article utilized a national (British) survey data set to determine strain compared to an emotional disorder group (Meltzer et al., 2011). These elements, discussed in length throughout the articles, will be briefly reviewed below.



### Impact on Caregivers' Psychological Well-Being

A study conducted by Manor-Binyamini (2012) analyzed parents' sense of coherence while caring for a youth with CD. This study incorporated 300 parents of children aged 6 to 18 with CD (selected from special education schools), and 100 parents of children without CD (selected from standard schooling systems) who served as a control group. The sense of coherence, as described by Antonovsky (1996), reviewed the following three mental states that an individual under stress must navigate: (a) comprehensibility (is the individual able to understand the unfolding situation?), (b) manageability (to what extent does the individual feel the situation is manageable; that is, are coping resources available?), and (c) meaningfulness (is the individual able to find meaning in their current situation?). Using Antonovsky's concept of sense of coherence, Manor-Binyamini (2012) investigated caregiver meaningfulness in addition to parental burden. The authors found that caregiver burden was higher for parents of children with CD, who also reported a lower sense of coherence compared to parents of children without CD.

### Impact on Caregivers' Relationships

CD places tension not only on caregivers exclusively but also on their relationships. One nationally representative UK study, which gathered data from 10,438 children throughout England, Wales and Scotland, found that parents of children with CD reported significantly higher levels of strain when compared to parents of children with emotional disorders (Meltzer et al., 2011). For example, 45.6% (n = 312) of participants raising a child with CD stated that their relationships have become "more strained" with their partner, 17.7% (n = 312) noted that their child's CD problems generated issues with their friends, and just over 25% (n = 312) of parents stated that this strain contributed to ending a previous relationship (Meltzer et al., 2011). Another study conducted in Iran (n = 23)included parents (n = 6), teachers (n = 5), and children aged 8-12 years diagnosed with CD (n = 5), along with social workers and psychology

experts (n = 7; Sajadi et al., 2020). The authors found through qualitative interviews that caregiver strain negatively impacted the quality of spousal relationships (Sajadi et al., 2020). For instance, parental relationship issues were almost exclusively associated with behaviour of a child with CD (Sajadi et al., 2020). Marital infidelity and "emotional divorce" (disconnect) were also reported to be prevalent problems in studied couples (Sajadi et al., 2020). These findings were corroborated by another research study (Chaudhury et al., 2020) on spousal problems in parents (n = 60) of youth with CD or Oppositional Defiant Disorder (ODD) in comparison with parents (n = 60) from a control group. ODD has some similarities to CD; however, the former is generally regarded as a less overt, or milder form of CD (Burke & Romano-Verthelvi, 2018). Spouses Chaudhury et al.'s (2020) study reported feelings of rejection by their partners, unmet affectional needs, helplessness, and lower levels of self-disclosure to their partners.

### **Impact on Parent-Child Relationship**

The parent-child (caregiver) relationship is crucial in a youth's formative years (Popov & Ilesanmi, 2015). CD/ODD has also been found to challenge this bond in areas of attachment, communication, and parental involvement (Chaudhury et al., 2020). First, parent-child attachment was hindered by the child's behaviour, as family conflicts likely worsened the already strained connection between youth with CD/ODD and their parents; second, communication between children and their parents was mostly conflictual as parents struggled to understand their externalizing behaviour; and third, while mothers struggled to empathize with their child with CD/ODD, fathers tended to limit their caregiving involvement (Chaudhury et al., 2020).

### **Discussion**

Caregivers face immense burden in their relationships throughout all aspects of their lives: from the caregiver's struggle to relate and empathize with their child/youth (Chaudhury et



al., 2020), to strained spousal relations (Sajadi et al., 2020), the impact of CD can at times be overwhelming for everyone involved in the caring process. These findings align with our initial predictions, which hypothesized that CD would generate an increase in strain and familial stress and decrease overall psychological wellbeing. However, there are numerous forms of interventions and therapeutic solutions while caring for CD youth that clinicians should consider (e.g., referral parenting programs). The role of clinicians treating CD in youth, especially during early intervention, is to be first and foremost a helping hand, listening to their anguish and assisting with future improvements (Carpenter, 2005). From these initial stepping stones, a shift toward holistic models of whole family care is crucial to assist youth with CD. Three areas of interest (prevalent themes in our review), which may go overlooked during clinical intakes and assessments, are the utility of parenting programs (Sanders et al., 2014), overarching neighbourhood effects (Jennings et al., 2018), and societal financial burden (Friedli & Parsonage, 2007; Scott et al., 2001). Each of the following three paragraphs will first present the area of interest, expressed as an integrated summary, and conclude with a related clinical recommendation.

### **Referral Parenting Programs**

Although not always widely accessible, due to geographical restrictions or financial constraints, caregivers may be offered support programs designed to reduce CD behavioural symptoms in both online and in-person training classes. Programs such as the Triple P-Positive Parenting Program (Sanders et al., 2014) focus on assisting caregivers with disruptive youth in developing skills and action plans aimed at reducing disorderly symptoms. The impact of the Triple P program has been shown to be substantial, with reductions in both caregiver depression and coercive parenting (Sanders et al., 2008), improvement in caregiver-youth relationships (Sanders et al., 2014), and an overall reduction in disruptive youth behaviours (Skotarczak & Lee, 2015). From a preliminary search, no research has been located that reviewed the impact Triple P had on caregiver strain while caring for a youth with CD; however, it is assumed that the success this parenting program has yielded in treating defiant behaviour would likely also be effective in treating CD symptomology. Based on these findings, clinicians may consider recommendations such as the Triple P-Parenting Program or other family training programs to help reduce strain and provide a support network for affected individuals.

### **Neighbourhood Effects**

A recent upsurge of published research has now shown the impact "neighbourhood effects" have on one's outcome with CD (Jennings et al., 2018). Specifically, the proximal environment where children grow up, including their neighbourhood, school, and play areas, is vital to their overall well-being (Minh et al., 2017). A recent literature review that incorporated 47 empirical studies from 2001 to 2016, reported a significant link between CD and neighbourhood effects (Jennings et al., 2018). From the clinician standpoint, perhaps the most imperative findings of the aforementioned literature review are not the factors that can increase CD symptoms, but rather, actions that may either prevent CD or improve its prognosis. Jennings et al.'s (2018) literature review indicated six prominent mediating moderating factors. Mediators relationships among neighbourhood effects, CD, and CD behaviours included stressful life events (Katz et al., 2012; Roosa et al., 2005), youth conflicts with peers and parents (Roosa et al., 2005), and maternal stress (Linares et al., 2001). Moderators included sex and ethnicity (Oshio, 2008), age (Riina et al., 2014), and parental monitoring (Glickman, 2003). Given these complex data, clinicians may favour ecological (multi-systems) family-based models, as either early preventive measures or interventions to reduce symptom severity.

#### Financial Burden

Another theme that emerged from the literature, although beyond the scope of this review, was financial burden. Substantial



differences in costs are found when comparing youth with CD to control groups. The largest contributing factors included criminality. educational costs, housing costs, state benefits, and health care (Scott et al., 2001). Another longitudinal American study incorporated participants from four distinct low socioeconomic communities. The researchers followed CD adolescents over a seven-year period. Compared to youth without CD, a substantial expense contrast was present, along with additional public expenditures (over seven years), that reportedly exceeded USD \$70,000 (CAD \$81,417; Foster et al., 2005). According to Foster et al. (2005) these costs are notably higher than comparable disorders such as ODD. Although the above findings review societal costs, low-income families will likely struggle to afford psychotherapy sessions, pharmacological treatments, and travel to access such services. mav Clinicians consider support navigational interventions to help families access financial assistance programs.

### **Conclusion**

It is clear that clinicians and support programs alike must work to assist caregivers, all the while understanding the plethora of genetic, psychological, and socio-economic factors that play a role in the etiology of CD. There may be a need for a shift of the focus on youth with CD toward resilience holistic intervention models for the whole family, community, and systems surrounding youth with CD or at-risk youth. Understanding the impact of CD on caregivers will allow mental health professionals to not only develop improved treatment plans but also provide a better family quality of life. This review was predominately limited in regard to available literature, as only four articles met our inclusion criteria; future studies may wish to expand keywords to incorporate disruptive behavioural disorders and isolate CD from ODD findings. Additionally, future studies may wish to incorporate articles published prior to the year 2000; although this review was restricted due to first co-author time constraints, older articles

may have been overlooked. This literature review summarized the limited available empirical studies of CD's impact on caregivers, which corroborated findings on adolescent depression (Armitage et al., 2020) and attention deficit hyperactivity disorder (ADHD; Evans et al., 2009). Caregiver strain was best predicted in carers of youth with ADHD who presented oppositional and delinquent behavioural patterns (Evans et al., 2009). Overall, this paper noted the immense strain CD places on caregivers, care providers and society at large.

#### References

- American Psychiatric Association. (2013).

  Diagnostic and statistical manual of
  mental disorders (5th ed.).
  https://doi.org/10.1176/appi.books.97
  80890425596
- Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11–18. https://doi.org/10.1093/heapro/11.1.1
- Armitage, S., Parkinson, M., Halligan, S., & Reynolds, S. (2020). Mothers' experiences of having an adolescent child with depression: An interpretative phenomenological analysis. *Journal of Child and Family Studies*, 29(6), 1617–1629. https://doi.org/10.1007/s10826-020-01705-5
- Burke, J. D., & Romano-Verthelyi, A. M. (2018).
  Oppositional defiant disorder. In M. M.
  Martel (Ed.), *Developmental pathways to disruptive, impulse-control, and conduct disorders* (pp. 21–52). Elsevier.
  https://doi.org/10.1016/B978-0-12-811323-3.00002-X
- Burt, S. A., & Klump, K. L. (2014). Parent-child conflict as an etiological moderator of childhood conduct problems: An example of a 'bioecological' geneenvironment interaction. *Psychological Medicine*, 44(5), 1065–1076. https://doi.org/10.1017/S0033291713 001190



- Carpenter, B. (2005). Early childhood intervention: Possibilities and prospects for professionals, families and children. *British Journal of Special Education*, 32(4), 176–183. https://doi.org/10.1111/j.1467-8578.2005.00394.x
- Chaudhury, P., Bhattacharya, B., & Saha, P. K. (2020). Parent-child relationship and marital quality of parents of conduct or oppositional defiant disorder and unaffected individuals: A comparative study. *Psychological Studies*, 65(2), 124–136. https://doi.org/10.1007/s12646-019-00543-w
- Evans, S. W., Sibley, M., Serpell, Z. N. (2009). Changes in caregiver strain over time in young adolescents with ADHD: The role of oppositional and delinquent behavior. *Journal of Attention Disorders,* 12(6), 516–524. https://doi.org/10.1177%2F10870547 08322987
- Foster, E. M., Jones, D. E., & The Conduct Problems Prevention Research Group. (2005). The high costs of aggression: Public expenditures resulting from conduct disorder. *American Journal of Public Health*, 95(10), 1767–1772. https://doi.org/10.2105/ajph.2004.061424
- Friedli, L., & Parsonage, M. (2007, November).

  Mental health promotion: Building an
  economic case. Northern Ireland
  Association for Mental Health.
  https://www.researchgate.net/publicat
  ion/308339133\_Mental\_health\_promoti
  on\_building\_an\_economic\_case
- Glickman, A. R. (2003). Parental monitoring of children exposed to community violence: Predicting externalizing behaviors (Publication No. 3096375) [Doctoral dissertation, University of Miami]. ProQuest Dissertations Publishing.
- Haber, J. R., Bucholz, K. K., Jacob, T., Grant, J. D., Scherrer, J. F., Sartor, C. E., Duncan, A. E., & Heath, A. (2010). Effect of paternal alcohol and drug dependence on offspring conduct disorder: Gene-

- environment interplay. *Journal of Studies on Alcohol and Drugs, 71*(5), 652–663. https://doi.org/10.15288/jsad.2010.71.652
- Jennings, W. G., Perez, N. M., & Reingle Gonzalez, J. M. (2018). Conduct disorder and neighborhood effects. *Annual Review of Clinical Psychology, 14*, 317– 341. https://doi.org/10.1146/annurevclinpsy-050817-084911
- Katz, B. N., Esparza, P., Carter, J. S., Grant, K. E., & Meyerson, D. A. (2012). Intervening processes in the relationship between neighborhood characteristics and psychological symptoms in urban youth. *The Journal of Early Adolescence*, 32(5), 650–680. https://doi.org/10.1177/02724316114 14060
- Linares, L. O., Heeren, T., Bronfman, E.,
  Zuckerman, B., Augustyn, M., & Tronick,
  E. (2001). A mediational model for the
  impact of exposure to community
  violence on early child behavior
  problems. *Child Development*, 72(2),
  639–652.
  https://doi.org/10.1111/14678624.00302
- Manor-Binyamini, I. (2012). Parenting children with conduct disorder in Israel:
  Caregiver burden and the sense of coherence. *Community Mental Health Journal*, 48(6), 781–785.
  https://doi.org/10.1007/s10597-011-9474-x
- Meltzer, H., Ford, T., Goodman, R., & Vostanis, P. (2011). The burden of caring for children with emotional or conduct disorders. *International Journal of Family Medicine*, 2011, Article 801203. https://doi.org/10.1155/2011/801203
- Minh, A., Muhajarine, N., Janus, M., Brownell, M., & Guhn, M. (2017). A review of neighborhood effects and early child development: How, where, and for whom, do neighborhoods matter? *Health & Place, 46,* 155–174.



- https://doi.org/10.1016/j.healthplace.2 017.04.012
- Oshio, T. (2008). A longitudinal examination of harsh discipline and externalizing behavior: An ecological perspective (Publication No. 3331988) [Doctoral dissertation, Michigan State University]. ProQuest Dissertations Publishing.
- Pardini, D., & Frick, P. J. (2013). Multiple developmental pathways to conduct disorder: Current conceptualizations and clinical implications. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 22(1), 20–25. https://www.cacap-acpea.org/wp-content/uploads/Multiple-Developmental-Pathways-Pardini.pdf
- Polanczyk, G. V., Salum, G. A., Sugaya, L. S., Caye, A., & Rohde, L. A. (2015). Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of Child Psychology and Psychiatry*, *56*(3), 345–365. https://doi.org/10.1111/jcpp.12381
- Popov, L. M., & Ilesanmi, R. A. (2015). Parent-child relationship: Peculiarities and outcome. *Review of European Studies*, 7(5), 253–263.
  - https://doi.org/10.5539/res.v7n5p253
- Riina, E. M., Martin, A., & Brooks-Gunn, J. (2014). Parent-to-child physical aggression, neighborhood cohesion, and development of children's internalizing and externalizing. *Journal of Applied Developmental Psychology*, 35(6), 468–477.
  - https://doi.org/10.1016/j.appdev.2014 .04.005
- Roosa, M. W., Deng, S., Ryu, E., Burrell, G. L., Tein, J.-Y, Jones, S., Lopez, V., & Crowder, S. (2005). Family and child characteristics linking neighborhood context and child externalizing behavior. *Journal of Marriage and Family*, 67(2), 515–529. https://doi.org/10.1111/j.0022-2445.2005.00132.x

- Sajadi, S., Raheb, G., Maarefvand, M., & Alhosseini, K. A. (2020). Family problems associated with conduct disorder perceived by patients, families and professionals. *Journal of Education and Health Promotion*, 9, Article 184. https://doi.org/10.4103/jehp.jehp\_110\_20
- Salvatore, J. E., & Dick, D. M. (2018). Genetic influences on conduct disorder. *Neuroscience and Biobehavioral Reviews,* 91, 91–101. https://doi.org/10.1016/j.neubiorev.20 16.06.034
- Sanders, M. R., Kirby, J. N., Tellegen, C. L., & Day, J. J. (2014). The Triple P-Positive Parenting Program: A systematic review and meta-analysis of a multilevel system of parenting support. *Clinical Psychology Review, 34*(4), 337–357. https://doi.org/10.1016/j.cpr.2014.04.003
- Sanders, M. R., Ralph, A., Sofronoff, K., Gardiner, P., Thompson, R., Dwyer, S., & Bidwell, K. (2008). Every family: A population approach to reducing behavioral and emotional problems in children making the transition to school. *The Journal of Primary Prevention*, 29(3), 197–222. https://doi.org/10.1007/s10935-008-0139-7
- Scott, S., Knapp, M., Henderson, J., & Maughan, B. (2001). Financial cost of social exclusion: Follow up study of antisocial children into adulthood. *BMJ*, 323. https://doi.org/10.1136/bmj.323.7306. 191
- Skotarczak, L., & Lee, G. K. (2015). Effects of parent management training programs on disruptive behavior for children with a developmental disability: A meta-analysis. *Research in Developmental Disabilities*, 38, 272–287. https://doi.org/10.1016/j.ridd.2014.12.004



### Research Article

### A Qualitative Case Study Exploring the Experiences of Caregivers Using a Patient Navigation Centre for Children with Complex Care Needs

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#### **Abstract**

**Introduction:** Approximately 15% of children in North America live with a complex health condition. When caring for these children, it can be difficult and time-consuming to determine what services are available to meet their complex needs. **Method:** The aim of this research project was to explore the experiences of families using NaviCare/SoinsNavi, a patient navigation centre for children/youth with complex care needs and their families. Six families were assessed longitudinally over a six- to eight-month period. Semi-structured interviews were done at intake, three to five months, and six to eight months. Families also kept a monthly diary recording their experiences. **Results:** Families were satisfied with the services provided by NaviCare/SoinsNavi. They found it comforting to have someone that would take the time to listen to their concerns and was able to provide recommendations for services. **Discussion:** This longitudinal case study shows the benefit of navigation centres for children/youth with complex care needs and their families.



### A Qualitative Case Study Exploring the Experiences of Caregivers Using a Patient Navigation Centre for Children with Complex Care Needs

### Introduction

Approximately 15% of children in North America experience a chronic health condition (Kaufman et al., 2007). These children often have unique health-care experiences that can make navigating the health care system challenging. They often require multiple visits to specialists and may require hospitalizations (Colver et al., 2013). While there is no single definition for a child with complex care needs, for the purpose of this study, this refers to a child or youth with "multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis..." (Brenner et al., 2018, p. 1647). These children are significant users of the health care system and related services, requiring a coordinated effort by the family as well as the care team.

The first patient navigation program was developed in Harlem, New York, by Dr. Harold Freeman in 1990 (Freeman & Rodriguez, 2011). Since that time, patient navigation has increased in use across North America. The aim of patient navigation is to guide and orient patients through the health care system, connecting patients' unmet needs appropriate resources to decrease fragmentation, improve access, and support the coordination of care (Fillion et al., 2012; Freeman & Rodriguez, 2011; McMullen, 2013). While the first patient navigation centres focused on cancer patients (Freeman & Rodriguez, 2011), it is becoming evident that patient navigation programs may be useful for other medically underserved populations, such as those who live in rural areas, due to the limited resources in these communities (Paskett et al., 2011; Weinhold & Gurtner, 2014). A recent environmental scan identified 19 pediatric patient navigator models in Canada (Luke et al., 2020). Patient navigation is an area of research that is increasingly shown to improve outcomes for children with complex care needs (American

Academy of Pediatrics Council on Children with Disabilities, 2005). However, studies exploring the experiences of participants using navigating services is limited. Navigating services and resources to meet the complex care needs of children can be especially difficult for families and even the care team (Charlton et al., 2017). Based on a needs assessment completed prior to 2017 with input from various stakeholders (Doucet et al., 2017), it was determined that there was a need for a patient navigation centre for children and youth with complex care needs and their families in New Brunswick, Canada (Charlton 2017). et al., NaviCare/SoinsNavi (NaviCare hereafter) was launched in January of 2017 (Doucet et al., 2019) with the following goals: (a) to ensure the integration of health, education, and social services for children and youth with complex care needs; (b) to advocate for children and youth with complex care needs and their families; and (c) to offer families a setting to voice their needs and mentor/support other families.

NaviCare is a free virtual research-based service that is available primarily through phone or email for children and youth (25 years of age or under), their family, and the care team. It is currently housed at the University of New Brunswick in Saint John. Families are connected to a patient navigator (PN) who is either a Registered Nurse or lay navigator. The ultimate goal of the PN is to coordinate access to services and resources and act as an integral part of the care team, helping children and youth and their families with their health-care journey. In the literature, there is limited research evaluating patient navigation, especially when dealing with navigation centres whose mandate involves children with complex care needs and their families.

### **Objective**

Patient navigation has been increasingly used to help integrate care since the 1990s and has expanded to include the pediatric population. There are few studies that highlight the experiences of caregivers who use these services. The aim of this research project was to



explore the experiences of caregivers of children and youth with complex care needs using NaviCare over three time points. This project is part of a larger program evaluation being undertaken to study the impact of NaviCare. Please see Luke et al. (2020) for additional details on the larger program evaluation.

### Methods

### Design

A longitudinal qualitative descriptive case study design (Yin, 2014, pp. 5–6) was used to explore the experiences of caregivers of families using NaviCare over three time points. Case studies allow the researcher to conduct an in-depth exploration of a subject over time.

### Sample

**Participants** were recruited to participate in the study when they first accessed the NaviCare service. Inclusion criteria included (a) being a client of the NaviCare services, and (b) were seeking navigational support for a child with a high level of complexity, being thus more likely to use the centre over an extended period. There were no exclusion criteria. For this study, "long-term" was defined as six months or more. In total, ten potential participants were identified by the PN. Their files were reviewed by the research leads, who confirmed whether each participant met the study inclusion criteria. The primary researcher called potential participants by phone and invited them to participate. If the family agreed, an initial interview was scheduled. If the families declined to participate, they did not have to provide an explanation why.

### **Ethics**

This project received ethics approval from the University of New Brunswick in Saint John (REB # 026-2016). The PN obtained verbal consent from the families on their willingness to be contacted by a member of the research team at their initial intake with NaviCare. Written consent to participate in the study was obtained

at the beginning of the initial interview. Participants were given \$100 in gift cards to a local grocery store for their participation. These gift cards were given as a \$25 gift card at the first and second interview and a \$50 gift card at the third interview. There were cases where additional family members, who did not give consent to be interviewed, were present and accidentally recorded at the time of the interview. In these circumstances, their comments were omitted and not transcribed. All recordings were deleted immediately following transcription.

### **Data Collection: Interviews and Diaries**

Two data collection methods were used to gain insight into the experiences of caregivers of families. These included traditional semi-structured interviews and the use of diaries to augment data collected from interviews.

Interviews were all conducted in person. Families were given the option to be interviewed in their home or another location of their choice. Participants were interviewed between 2017 and 2019. Participants were given the option to be interviewed in English or French. All participants opted to be interviewed in English, and translational services were not required.

Semi-structured interviews were conducted at three points in time: intake, three to five months, and six to eight months. The same interview guide was used for all three interviews. Interview questions were designed with open-ended questions to allow participants to fully express their experiences and guide the interview. Interview questions were divided into five categories: (a) Satisfaction/experience with NaviCare; (b) Knowledge gained from accessing NaviCare; (c) Experiences with coordination, integration, and continuity of care; (d) Changes in quality of life; and (e) Suggestions for improvement of the centre. Interviews were recorded, and each lasted approximately 20 minutes.

At intake, participants were also asked to keep a monthly diary to record their experiences. Participants were provided with an



iPod touch and paper diary and were given the option to record their entries using an audio, video or written diary format. A diary guide was provided in both English and French to assist participants; however, they were informed that the content of the diaries could be creative to reflect their own experiences with NaviCare. The diary guide prompted participants to both positive and document negative experiences using NaviCare. The use of diaries allows experiences to be recorded in close temporal proximity to their occurrence, which contrasts with more traditional qualitative methods, such as semi-structured interviews, in which there may be a span of time between an experience and the recording of that experience (Bolger et al., 2003).

### **Data Analysis**

Interviews and diary data were transcribed verbatim. Transcription of both the interviews and diaries were done solely by the principal researcher. Transcripts were read over by the primary researcher for accuracy. Transcripts were de-identified, and participants were assigned a code. Both interview and diary data were analyzed together with the intention that diary data would enrich the interview data. The lead author used Microsoft Word with the highlight function to extract codes and identify themes. The lead author met with co-authors to review codes and themes. The analysis was guided by Braun and Clarke's six phases for thematic analysis (Braun & Clarke, 2006), which are the following:

- 1. familiarization with the data,
- 2. generation of initial codes,
- 3. search for themes,
- 4. review of themes,
- 5. definition and naming of themes
- 6. generation of a report.

### Results

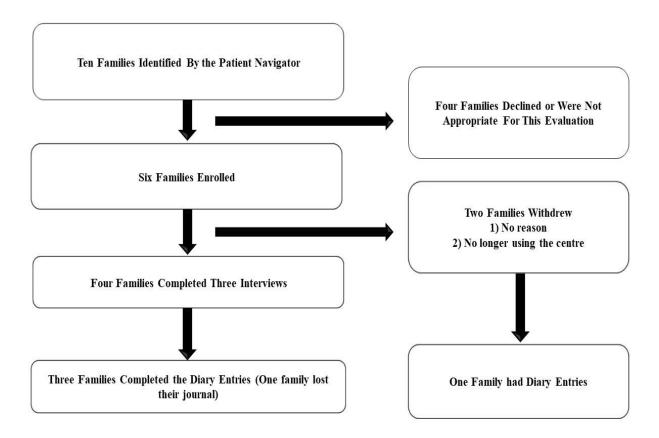
In total, ten families were identified by the PN and subsequently contacted by the research team. Four families were not included in the study: three of these families declined to participate, while one other family was not deemed to be appropriate as they did not anticipate using the centre long-term (over 6 months). Families that declined did not provide a reason as to why they did not want to participate in the study. Six families were initially enrolled in the case study. Their demographic information is included in Table 1. Four of these families completed the case study, while two others completed one interview but withdrew afterwards (Figure 1). From the six families initially enrolled, five participants were mothers, and one was a grandmother. All participants were the child/youth's primary caregiver. Data from withdrawn participants was included in the study with their consent. All interviews were conducted in the participant's home as preferred by the participant. All participants opted to be interviewed in English.

One of the final four participants did not complete the diary entries. This participant informed the research lead at the final interview and diary collection that they had lost their

**Table 1**Demographic Information from Participants

Participant	Relationship to	Primary Language	Condition of	Age of	Sex of
Number	Child	Spoken	Child	Child	Child
3	Grandmother	French	Neurological	8	M
5	Mother	English	Mental Health	10	M
6	Mother	English	No Diagnosis	8	M
8	Mother	English	Cardiac	16	M
9	Mother	English	Gastrointestinal	3	M
10	Mother	English	Neurological	9	F





**Figure 1**Outline of Patient Enrollment in Study

*Note.* An outline of patient enrollment, including the number of families that completed the three semi-structured interviews and diary entries.

diary. They were not excluded from the study and their interview data was analyzed. One family that withdrew partway through the study completed four diary entries. Three participants preferred to use written diaries, while one used the iPod for audio diary entries. Table 2 outlines details of the diary entries.

### Themes Emerging from Interviews and Diaries

Based on the transcripts, codes were used to determine themes from both interview and diary data. In general, data emerging from diaries coincided with interview data. In addition, diary data provided additional details about programs and services suggested by the PN that participants could not remember at the time of the interview. There were five main

themes that emerged from the data: (a) a strong sense of support, (b) sharing knowledge, (c) improved communication with the care team, (d) quality of life and (e) suggestions to improve the navigation centre.

### Theme 1: A Strong Sense of Support

All participants described being satisfied with the services provided by NaviCare. Participants felt that the PN was a strong pillar of support. They regularly described situations where they felt overwhelmed and found that the PN provided the emotional support required to care for their child.

... the [PN] kept me going while everything was really stressful, they were very supportive. And having two children with special needs, one with extreme



special needs is difficult. And when you are fighting a battle to get help and care knowing that I had two people that I could call at any time that, yeah that made the difference... (Participant 5)

Multiple caregivers of families described feeling alone and not heard by the system. In these situations, participants found that NaviCare was able to provide support by carefully listening to parents and what they had to say.

Especially people who have chronically ill children and you don't have a diagnosis it becomes extremely frustrating and you feel alone. Like sometimes you feel like oh yeah no no they are listening but they aren't hearing what you are saying [...] you know that validation that it's okay, we are going to get to the bottom of this and I'm going to help you get there. (Participant 9)

In addition to support from the PN, some participants also mentioned that they felt they would benefit from the creation of a support group for parents who have children with complex care needs.

### Theme 2: Sharing Knowledge

In general, caregivers of families were happy with the PN's knowledge of available programs and services. The PN was found to have provided recommendations for a large variety of programs and services. Different caregivers requested different services based on their needs. As an example, some participants felt very comfortable navigating the health care system but struggled to navigate government programs or the school system. In these cases, the PN provided information about tax reimbursements, the Department of Social Development, forms for schools and letters of support. Other caregivers felt as though they struggled with accessing health-care services locally. In these cases, the PN helped by contacting pediatricians and informing parents about services such as respite care, dietetics and multidisciplinary teams. One family developed a strong working relationship with the PN where they would share information and inform the PN about services and programs that they may not have been aware of. As one participant stated, "So, they kinda learned some stuff from me and I learned some stuff from them. So, it was kinda a teachable moment for both of us" (Participant 5).

During their second interview, one participant described finding a program themselves and wishing that NaviCare had directed them there earlier. This is discussed further below under the theme "Suggestions to improve the navigation centre". Participants also commented on learning about programs from other services that they were originally directed to by NaviCare. For example, the PN connected one family with a social worker, who then referred them to additional resources. As stated by this participant, "without one it wouldn't have led to the other" (Participant 10).

**Table 2**Details of the Diary Entries

Participant	Number of Interviews	Number of Diary Entries	Type of Diary	Avg. Length of Diary Entry
3	3	0	N/A	N/A
5	3	8	Written	25 words
6	1	0	N/A	N/A
8	1	4	Audio	1 min 30 sec
9	3	7	Written	206 words
10	3	6	Written	43 words



### Theme 3: Improved Communication with the Care Team

Participants felt as though communication with the care team was improved. The PN communicated with various members of the care team, in some cases expediting appointments with pediatricians and other health-care providers. As stated by one participant, "I found that it really helped me communicate with the other people looking after [Son]" (Participant 9).

Parents found that having the PN advocate and communicate on their behalf made other health-care providers pay more attention to their concerns. Participants also found that the PN helped them better prepare for visits with health-care professionals, advising them to make a list of questions they should ask at these appointments.

### Theme 4: Mixed Responses Concerning Quality of Life

Some participants describe an improvement in the baseline of their quality of life after contacting NaviCare. They found that the PN helped decrease the amount of work they had to do. One participant commented that "[the PN] has been able to take some off of my plate for me ... so it kind of lessens the load" (Participant 5).

While none of the participants described having their quality of life decrease after calling NaviCare, some participants describe no change in baseline of their quality of life: "My quality of life, no I would say it's the same. It's the same, yeah" (Participant 3).

### Theme 5: Suggestions to Improve the Navigation Centre

Participants were asked what suggestions they had to improve NaviCare. While most participants were happy with the services provided, one participant believed that NaviCare should increase the repertoire of services recommended by the PN: "We discovered there is a camp for children and adults living with disabilities. I think this is something that should be added to the services NaviCare help with" (Participant 10).

Based on factors beyond the control of the centre, there was a switch in the PN during the time period in which this longitudinal study took place. Two participants commented on how there was a period where they were not contacted, which left them wondering if the service was still running. One of these participants commented on how part of what they loved about NaviCare was that they did not have to repeat their story multiple times. Having this switch was quite difficult for them, as they relied heavily on the prior PN for support and were wary about becoming attached to a new PN. This difficulty was reflected in one client's diary and had an impact on their experience with the centre.

Another suggestion brought to light by participants was the need for an increase in marketing and promotion for the centre. Participants found that other parents in their social circles who they believe would benefit from NaviCare were unaware of the service. Additionally, participants found that they would have to explain what NaviCare was to health-care professionals. Finally, participants found that they would like to have a face-to-face meeting with the PN to see who the person was on the other end of the phone.

### **Discussion**

The aim of this research project was to explore the experiences of caregivers of children and youth with complex care needs using NaviCare over three time points. There were five main themes that emerged from the data: (a) a strong sense of support, (b) sharing knowledge, (c) improved communication with the care team, (d) quality of life and (e) suggestions to improve the navigation centre.

All participants were satisfied with the services provided by NaviCare. The most recurring theme among all participants was that they found NaviCare to be a pillar of support. Prior to contacting the centre, participants felt alone and not taken seriously by the health care system. NaviCare was a service that helped validate their concerns and helped them through tough situations by providing



emotional support. Participants felt as though they would benefit from a support group for parents with children with complex care needs. This is consistent with a scoping review done by King et al. (2017) on family-oriented services in pediatric rehabilitation in which caregivers identified the need for emotional support. Other studies have highlighted that being a caregiver of children with complex care needs can have an impact on emotional and mental health (Caicedo, 2014; Ellenwood & Jenkins, 2007). It appears that NaviCare is filling that role of a support group for parents by providing an environment where parents were able to express their concerns to someone who has the time to address and validate them. This mirrors other programs that use PNs. As an example, a study by Gotlib Conn et al. (2016), which followed a patient navigation service for cancer patients, demonstrated that PNs provided holistic support, including emotional support to participants and their families.

In general, participants were satisfied with the number of services and resources recommended by the PN and by the improvement in the coordination of their child's care as a result of the PN bringing the team together. This is in keeping with not only the original aims of the centre, but also with other patient navigation programs whose outcomes include increased communication with services and care providers and increased patient satisfaction regarding services (Valaitis et al., 2017). The theme "sharing knowledge" also highlighted the back-and-forth relationship that caregivers have with the PN. Participant 5 was quoted saying "So, they kinda learned some stuff from me and I learned some stuff from them. So, it was kinda a teachable moment for both of us." The caregivers themselves are also a wealth of knowledge.

Interestingly, while most participants were satisfied with the services, the effects on quality of life were mixed among participants. Participants whose quality of life was unchanged involved cases that were not yet resolved (i.e., they remain clients of the centre). As an example, one participant interviewed in the summer months was scheduled to start

receiving respite care for their child in the school year. This participant postulated that their quality of life would improve once they had a care worker who could start coming during the school year. In contrast, participants whose quality of life had improved had found services that helped them cope with their child's complex care needs. In the literature, the effects of patient navigation on quality of life are mixed (Paskett et al., 2011). However, a more recent study by King et al., (2017) suggested that PN services can help lessen the burden of caregivers and improve the caregiver experience. Given that these children have complex care needs. longer term studies will likely be required to determine if there is a trend of improvement in quality of life.

### Limitations

One limitation of this study is the small sample size. Moreover, given that the PN flagged participants who might be long-term cases with NaviCare, this potentially introduced bias as only flagged participants were contacted for enrollment in the study. The participants were required to self-report satisfaction experience, which is dependent on participants' recall and recollection. Although participants were informed that only the research team had access to the findings, the information shared may have been limited, as participants may have not wanted to give negative feedback for fear that it may get back to the PN. An additional limitation is that the centre was in the pilot stages when the data for this study was collected. Waiting until the early kinks were ironed out may have led to differences in the reported experiences. Finally, the average interview time was short, at approximately 20 minutes, which may have been too little time to generate answers.

### **Recommendations for Navigation Centres**

Our recommendations for patient navigation programs are based on the suggestions from participants of this qualitative study. The first recommendation is to ensure



proper marketing of a new navigational centre. Participants found it difficult having to explain NaviCare was to other parents. organizations, and health-care providers. They suggested increased marketing and promotion of the centre to make it more well known. Our suggestion for this would be to present the centre at Grand Rounds teaching events at children's hospitals and education centres. In addition, the PN could provide caregivers with materials to present to health-care providers that describe the navigation program services, which could help parents avoid repeating themselves. Our second recommendation would be that, when there is a transition between PNs. a meeting should be arranged between the ingoing and outgoing PN and the client to ease the disruption of the transition as was discussed in the limitations. Our final recommendation is that PNs consistently check in with stakeholders providing programs and services for the population they are serving, to ensure that the centre's repertoire of programs and services is up to date. Participant 5 was quoted above highlighting the back-and-forth relationship between caregivers and the PN.

#### Conclusion

All caregivers stated that they were satisfied with the services provided by NaviCare and found it to be a beneficial service. In particular, the PN was a primary source of emotional support for many parents, helping them through difficult situations. In general, this qualitative longitudinal descriptive case study demonstrates the benefit of patient navigation programs that focus on children with complex care needs and their families.

### References

American Academy of Pediatrics Council on Children with Disabilities. (2005). Care coordination in the medical home: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, 116(5), 1238–1244.

- https://doi.org/10.1542/peds.2005-2070
- Bolger, N., Davis, A., & Rafaeli, E. (2003). Diary methods: Capturing life as it is lived. *Annual Review of Psychology, 54*, 579–616. https://doi.org/10.1146/annurev.psyc h.54.101601.145030
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://psycnet.apa.org/doi/10.1191/1478088706qp063oa
- Brenner, M., Kidston, C., Hilliard, C., Coyne, I., Eustace-Cook, J., Doyle, C., Begley, T., & Barrett, M. J. (2018). Children's complex care needs: A systematic concept analysis of multidisciplinary language. *European Journal of Pediatrics, 177*(11), 1641–1652. https://doi.org/10.1007/s00431-018-3216-9
- Caicedo, C. (2014). Families with special needs children: Family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association,* 20(6), 398–407. https://doi.org/10.1177%2F10783903 14561326
- Charlton, P., Azar, R., Luke, A., Doucet, S.,
  Montelpare, W., Nagel, D., Hyndman, N.,
  & Thompson, K. (2017). Falling through
  the cracks: Barriers to accessing
  services for children with complex
  health conditions and their families in
  New Brunswick. Journal of New
  Brunswick Studies / Revue D'études Sur
  Le Nouveau-Brunswick, 8, 133–158.
  https://journals.lib.unb.ca/index.php/J
  NBS/article/view/25883
- Colver, A. F., Merrick, H., Deverill, M., Le Couteur, A., Parr, J., Pearce, M. S., Rapley, T., Vale, L., Watson, R., & McConachie, H. (2013). Study protocol: Longitudinal study of the transition of young people with complex health needs from child to adult health services. *BMC Public Health*, 13, Article 675.



- https://doi.org/10.1186/1471-2458-13-675
- Doucet, S., Luke, A., Splane, J., & Azar, R. (2019). Patient navigation as an approach to improve the integration of care: The case of NaviCare/SoinsNavi. *International Journal of Integrated Care*, 19(4), Article 7.

http://doi.org/10.5334/ijic.4648

- Doucet, S., Nagel, D. A., Azar, R., Montelpare, W. J., Charlton, P., Hyndman, N., Luke, A., & Stoddard, R. (2017). A mixed-methods Quick Strike research protocol to learn about children with complex health conditions and their families.

  International Journal of Qualitative Methods, 16(1).

  https://doi.org/10.1177%2F16094069 17731426
- Ellenwood, A. E., & Jenkins, J. E. (2007).

  Unbalancing the effects of chronic illness: Non-traditional family therapy assessment and intervention approach.

  The American Journal of Family Therapy, 35(3), 265–277.

  https://doi.org/10.1080/01926180600 968431
- Fillion, L., Cook, S., Veillette, A. M., Aubin, M., de Serres, M., Rainville, F., Fitch, M., & Doll, R. (2012). Professional navigation framework: Elaboration and validation in a Canadian context. *Oncology Nursing Forum*, *39*(1), E58–69. https://doi.org/10.1188/12.onf.e58-e69
- Freeman, H. P., & Rodriguez, R. L. (2011). History and principles of patient navigation. *Cancer*, *117*(S15), 3539–3542.
- https://doi.org/10.1002/cncr.26262
  Gotlib Conn, L., Hammond Mobilio, M., Rotstein, O. D., & Blacker, S. (2016). Cancer patient experience with navigation service in an urban hospital setting: A qualitative study. *European Journal of Cancer Care*, 25(1), 132–140. https://doi.org/10.1111/ecc.12247
- Kaufman, M., Pinzon, J., Canadian Paediatric Society, & Adolescent Health

- Committee. (2007). Transition to adult care for youth with special health care needs. *Paediatrics & Child Health, 12*(9), 785–788.
- https://doi.org/10.1093/pch/12.9.785
- King, G., Williams, L., & Hahn Goldberg, S. (2017). Family-oriented services in pediatric rehabilitation: A scoping review and framework to promote parent and family wellness. *Child: Care, Health and Development, 43*(3), 334–347.
- https://doi.org/10.1111/cch.12435
- Luke, A., Luck, K. E., & Doucet, S. (2020).

  Experiences of caregivers as clients of a patient navigation program for children and youth with complex care needs: A qualitative descriptive study.

  International Journal of Integrated Care, 20(4), Article 10.

  http://doi.org/10.5334/ijic.5451
- McMullen, L. (2013). Oncology nurse navigators and the continuum of cancer care. Seminars in Oncology Nursing, 29(2), 105–117. https://doi.org/10.1016/j.soncn.2013.02.005
- Paskett, E. D., Harrop, J. P., & Wells, K. J. (2011). Patient navigation: An update on the state of the science. *CA: A Cancer Journal for Clinicians*, *61*(4), 237–249. https://doi.org/10.3322/caac.20111
- Valaitis, R. K., Carter, N., Lam, A., Nicholl, J., Feather, J., & Cleghorn, L. (2017). Implementation and maintenance of patient navigation programs linking primary care with community-based health and social services: A scoping literature review. *BMC Health Services Research*, 17, Article 116. https://doi.org/10.1186/s12913-017-2046-1
- Weinhold, I., & Gurtner, S. (2014).

  Understanding shortages of sufficient health care in rural areas. *Health Policy* (Amsterdam, Netherlands), 118(2), 201–214. https://doi.org/10.1016/j.healthpol.2014.07.018
- Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.). Sage Publication.



### Research Article

### Interprofessional Collaboration in the Care of Children With Complex Care Needs: The Experiences of Children, Their Families, and the Intersectoral Care Team

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#### Abstract

Introduction: Coordinated care has the potential to provide positive outcomes for children with complex care needs (CCN) and their caregivers. This population requires a multitude of services that are administered by various providers across sectors. Research has shown that care for this demographic can be improved through interprofessional care models and communication among providers. The primary objective of this study was to explore the barriers to collaboration among members of the care team. The second objective was to identify ways to improve coordination between caregivers and providers. **Methods:** This qualitative study focused on the perspectives of caregivers of children with CCN, health professionals, educators, and social care providers regarding their experiences with interprofessional collaboration in the care of children with CCN and their families in two Atlantic Canadian provinces (New Brunswick and Prince Edward Island). The study was conducted using semi-structured interviews of 32 family members and 88 stakeholders from the educational, health, and social sectors. Interview data were analyzed using thematic analysis (Braun & Clarke, 2006). Results: Participants included caregivers, health-care providers, educators, social workers, and therapists. All participants were involved in the care of children with CCN. Findings indicate that participants experience difficulties when accessing primary care and support services for children with CCN. These barriers were correlated with fragmented and uncoordinated care. Results were organized into three main themes: (a) Role Clarification, (b) Communication, and (c) Patient/Family-Centred Care. Each theme was explained through subthemes highlighting experiences of caregivers and care providers across sectors. **Discussion:** This study emphasized the need for increased research and evidence-based practices to address the current barriers to collaboration among care providers and caregivers when caring for children with CCN. By providing a patient-centred approach, there is opportunity to improve collaboration among providers and with caregivers while meeting the care needs of children with CCN.

<u>Keywords:</u> interprofessional, communication, disability, child, caregiver, care coordination, medical complexities



Interprofessional Collaboration in the Care of Children with Complex Care Needs: The Experiences of Children, Their Families, and the Intersectoral Care Team

The worldwide incidence of children with complex care needs (CCN) under the age of 14 has increased over the last decade (Brenner et al., 2018; UNICEF, 2013; World Health Organization, 2011). In Canada, the number of children with complex health needs is reported to be 3.7% of the pediatric population (Statistics Canada, 2008). A child with CCN refers to multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They individual are contextualized, are continuing and dynamic, and are present across a range of settings, impacted by healthcare structure (Brenner et al., 2018, p. 1647).

This population is defined as having complex disorders, multiple chronic conditions and/or genetic conditions. A few examples of these complexities are autism spectrum disorder, global developmental delay, brain and spinal cord malfunction, muscular dystrophies, heart malformations, cystic fibrosis, Down syndrome, and cerebral palsy. This population children presents challenges coordinating care due to their medical complexities (Cohen et al., 2011). This population requires a multi-faceted level of care from a wide range of providers across health, education, and social services (McPherson et al., 1998; World Health Organization, 2011).

As the prevalence of children with CCN increases, there is a demand to focus on improving the current health-care landscape for this population (Barnert et al., 2019; Looman et al., 2020; Shimmura & Tadaka, 2018). Without access to services and providers, caregivers of children with CCN must resort to constant trips to the emergency room or large city centres with specialized professionals to receive the care their child needs. There has been increased attention paid to research focusing on children with CCN in the last decade (Barnert et al., 2019; Cohen et al., 2018). This focus has primarily

aimed attention at the prevalence of this population, the program interventions that need to be put in place to best address their needs, and health care system costs (Cohen et al., 2018; Looman et al., 2020; Shimmura & Tadaka, 2018). A majority of the studies focused on using a coordinated care approach in either hospital settings or primary-care models to support the care of children with CCN (Barnert et al., 2019; Boudreau et al., 2014; Cohen et al., 2018; Looman et al., 2020; Shimmura & Tadaka, 2018). The studies that promoted the use of interprofessional care for children with CCN were conducted primarily within the United States. Study designs varied, but the majority were conducted using a scoping or systematic review of the literature or a cross-sectional study using questionnaires or observations, while one article analyzed the quantitative data from a national survey. The body of literature for this population is still small, and more research needs to be directed toward finding ways to improve care for children with CCN and their families (Barnert et al., 2019; Boudreau et al., 2014; Brenner et al., 2018; Cohen et al., 2018; Looman et al., 2020; Shimmura & Tadaka, 2018).

The importance of delivering patientfocused care that addresses the needs of those requiring medical attention is widely recognized (Barnert et al., 2019; Boudreau et al., 2014; Cohen et al., 2018; Looman et al., 2020). As stated above, recent evidence emphasizes the lack of patient satisfaction across health-care settings, a concern that could be addressed through interprofessional collaboration among the intersectoral team (Barnert et al., 2019; Looman et al., 2020). Interprofessional collaborative practice focuses on highlighting the knowledge, skills, attitudes and values of care providers by integrating six competency domains: (a) interprofessional communication, patient/client/family/community-centred care, (c) role clarification, (d) team functioning, (e) collaborative leadership, and interprofessional conflict resolution (Canadian Interprofessional Health Collaborative, 2010). Through the integration of these six domains, health workers can work to facilitate a dynamic foundation for interprofessional learning and



practice, improving health-care access and quality across sectors (Stewart, 2018). This study was part of a larger study exploring the needs of children with CCN and their families. After an analysis of the interviews from the larger study was completed, the findings indicated need a clear to improve communication among those providing care and support for children with CCN. The primary objective of this study was to explore the barriers to collaboration among members of the care team. The second objective was to identify ways to improve coordination between caregivers and providers.

### **Purpose of the Study**

Children with CCN require a multitude of services that are arranged by various providers across sectors. Research has shown that care for this demographic can be improved through interprofessional care models communication among providers. The purpose of this study was to explore the perspectives of caregivers, health professionals, educators, and social care providers regarding experiences with interprofessional collaboration in the care of children with CCN and their families in two Atlantic Canadian provinces.

### Methods

This research study is part of a larger mixed-methods project exploring the needs of children with CCN and their families. Further details on the research protocol are published in Doucet et al. (2017). Employing a qualitative descriptive design, this study examined the experiences of children, their families, and members of the team care with interprofessional collaboration in the care of children with CCN and their families. This study took place in two Canadian provinces: New Brunswick (NB) and Prince Edward Island (PE) in 2016. NB and PE are sparsely populated, with nearly half of the population located in rural areas. In addition, NB is a bilingual province with both English- and French-speaking residents. Letters were sent by mail, electronically and traditionally, to eligible participants. The 120

eligible participants were either interviewed individually (n = 97) or attended a focus group (n = 23) and comprised the following: children with CCN (n = 5); family members of children with CCN (n = 32); health professionals (n = 40); education professionals (n = 17); and social care professionals (n = 26). All interviews were conducted in person using an open-ended format. The interviews question audiotaped and transcribed verbatim. For the purpose of this study, only the perspectives of caregivers of children with CCN and the care team were included. The interviews of children with CCN were thematically analyzed; however, the answers they provided to the questions were not relevant to the objective of the study. Their interviews have been used in the larger research study. The interviews used open-ended questions to allow the opportunity for participants to describe their experiences in a first-person narrative. The questions explored the needs of children with CCN and their families, the role of the care team, and the gaps and barriers in each province. Separate questions were asked to caregivers and the care team that related to their role in providing support to children with CCN. Ethics approval was obtained prior to recruitment and data collection and, following an explanation of the study, all participants provided informed consent. Ethics approval for this project was received from (a) University of New Brunswick—Saint John (#023-2015), (b) Mount Alison University (#2016-044), (c) University of Prince Edward Island (#6006412), (d) Horizon Health Network in NB (#20162329), and (e) the PEI Research Ethics Board (no file #). Transcribed interviews were analyzed using Braun and Clarke's (2006) six phases of inductive thematic analysis. Following these guidelines, themes were developed and refined through a collaborative team approach among the authors.

### Results

A range of concerns surrounding interprofessional care for children with CCN were identified through stakeholder and caregiver interviews. Key quotes from



interviews were selected to reflect overarching themes from the study. Quotes from caregivers (C), health professionals (HP), and educators (E) were chosen to be included. The limitations to providing optimal care to children with CCN were recognized and organized into three themes: (a) role clarification, (b) communication, and (c) patient/family-centred care. Table 1 provides an overview of the main themes and subthemes.

### **Role Clarification**

Participants noted that clear roles and responsibilities for each member of the care team will provide them with a clear definition of their position and indicate what gaps need to be addressed. This first theme includes two subthemes: (a) education and knowledge of care providers, and (b) team structure.

### Education and Knowledge of Care Providers

Stakeholders found it challenging to focus on providing only their scope of practice for children with CCN. The limited number of

care providers forces stakeholders to not only provide their scope of care, but also act as a source of support or have knowledge in areas outside of their expertise. One concern of caregivers was the lack of education stakeholders had when caring for children with CCN. Without this quality of knowledge and education, stakeholders are not delivering the highest quality of care to patients. One caregiver stated the need for stakeholders to be educated on the latest evidence-based research when providing care for children with CCN:

I would think no children with any amount of complexity would have much of anything done in Saint John anymore. There was a time when all of their G-tubes would have been done here and the trachs would have been done here and that kind of stuff under the name of a generalist. Not even just complex kids but simple surgical procedures, it's hit or miss whether it would be done here now depending on the comfort level of the person who is on call. (C)

**Table 1** *Themes and Subthemes* 

Themes	Subthemes
Role Clarification	a) Education and knowledge of care providers
	b) Team structure
Communication	a) Interpersonal (between care providers)
	b) Technology (to facilitate the transfer of information
	between care providers)
	c) Privacy (barriers communicating with providers across
	departments and provinces.
Patient/Family-Centred Care	a) Repeating their story
	b) Involvement in care plan



#### Team Structure

Lack of communication when navigating a provider's role in the care plan of the child was addressed in the interviews. A stakeholder spoke about the lack of structure and sharing of knowledge regarding a child's care plan:

Sometimes difficulty we find collaborating with schools for example. Some schools are more open to collaboration meetings, and some schools are totally not. They just don't want to meet. They refuse to meet, and they don't get us involved in meetings if they're meeting with families. Even knowing that we're involved in the care of the child, so this kind of collaboration really is necessary and we should try to break this silo of education and health system and social services. They, we really should collaborate more and we are not. (HP)

#### **Communication**

The second theme refers to effective communication. This can be defined as methods of relaying information, either verbally or in other forms, to those involved. If either party lacks a clear understanding of the information exchanged, the communication can be jeopardized. Communication is multi-faceted and includes three subthemes: (a) interpersonal, (b) technology, and (c) privacy.

#### *Interpersonal*

Communication among providers is still a current barrier that needs to be addressed to provide optimal patient care. One stakeholder commented on the communication barriers between providers:

I think communication and roots of communication tend to be the biggest barriers. Most fields work in their own niche and despite the overuse of the term, most sectors are silo-ed. I think without the proper channels to communicate, often we're not working together toward the best end and that certainly isn't good for anyone! (HP)

Another stakeholder also commented on the problems that currently occur when stakeholders are trying to collaborate on a patient's care:

Well, sometimes it's a barrier because there's multiple people involved in the care of a child. Trying to stay in touch with everybody and coordinate everybody can just be logistically a challenge. Sometimes people aren't always easy to reach. Sometimes you end up playing phone tag through the best of efforts with people to try and coordinate. (HP)

The barriers to communication among care providers within the health care system needs to be addressed.

#### **Technology**

A common problem among stakeholders was the lack of consistency when accessing information on individual patients. Referrals between stakeholders can get lost or delayed due to current inefficient methods of communication being utilized. One health-care worker described the complications that can occur when there is more than one type of health-care charting system being used:

There's different charting systems too, depending on where you're located. So, at the hospital, for example, we do paper charting for outpatients, but then for inpatients we use a system called Cerner. Whereas like, the speech therapist and dieticians and so on, use a system called ISM and those two systems are not compatible with each other. (HP)

#### Privacy

Stakeholders discussed some of the current issues surrounding confidentiality when communicating within the care team. This included the sharing of patient information among providers from different sectors (e.g., education, health, social services, government). One health-care provider expressed their apprehension surrounding privacy concerns:



Some of it has to [do] with something simple, even like confidentiality, because every organization has different regulations around what they're allowed to share and what they're not allowed to share and at what age a child is considered adult. So, what we're allowed to share even around the table is not the same, unless they eliminate that barrier as well. (HP)

Privacy laws also restrict the information shared between stakeholders in different provinces. One stakeholder acknowledged the complications when dealing with cross-province care:

Services and sharing that information with outside of the province services and then getting information back from those outside of province services in a timely manner so we're able to help support families and their children to follow up on any of those recommendations and so sometimes there is good communication both ways and sometimes that doesn't work so, it's just not as timely and efficient as it could be. (E)

#### **Patient/Family-Centred Care**

The third theme reflects the need for a model of care that is more patient or family centred. Participants reported a need for an approach to care that is responsive and respectful of the patient's needs and requires a partnership between those receiving care and the care provider. This theme, patient/family-centred care, has two subthemes: (a) repeating their story and (b) involvement in care plan.

#### Repeating Their Story

Many caregivers felt frustrated when they constantly had to repeat their child's medical history and needs at every appointment. They expressed their desire to be included in the care plan but did not want to be relied upon as the sole source of information. One caregiver stated,

So, although they are really great because they know when I go in there that I have all this background and they really, I mean they listen to me as kind of the expert on that to help guide them. It would just be nice if they had more information, so it wasn't me. (C)

Another caregiver commented on how a coordinated care plan would help ensure they did not have to repeat their child's story numerous times:

Well the fact that all those services would be in one place, one location, would be a big thing in itself. I don't imagine it would be the family having to share their story over and over and over with many different doctors and many different service providers. They would share that once and that would be it and there to help you. I believe that, just the idea itself is a very positive thing and the outcomes are probably going to be very good. (C)

#### Involvement in Care Plan

Caregivers and family members also expressed their desire to be a part of the planning process for the child's care plan. Most caregivers felt they were not listened to, or did not have a say in the plan being provided. A stakeholder commented on the benefits of using a coordinated model of care:

Their distinct needs are that they need a coordinated team approach that will help them to understand everything that's going on with their child and all the different services that need to be involved. And, how all those are coordinated. So, I think, because, a lot of the families can be overwhelmed by just the illness and then all the different people that they may have to see. (HP)

Addressing ways to improve the caregiver's involvement in the child's plan is necessary. A caregiver commented on how to improve knowledge family-centred care:



When you have interprofessional team members sitting on a team, then the knowledge, talent, that they do bring to the teams, and having that child and that family at the centre, and the recovery-based approach would follow the pathway of that child and making sure that we only provide the least restrictive measures and in trying to address the needs of that child. (C)

By collaborating, stakeholders would be able to work together and communicate effectively to optimize the way patients are currently being supported.

#### **Discussion**

This study sought to better understand the gaps to accessing coordinated care for children with CCN. This study identified the current knowledge gap among providers as well as the need to improve communication across disciplines to focus on a patient-centred care approach. Caring for children with CCN is challenging, each child needs as individualized and dynamic plan involving a range of care providers (Brenner et al., 2018). Previous studies have demonstrated that caregivers of children with CCN experience distress and emotional burden as a result of inadequate support from professionals (Brehaut & Kohen, 2016; Brenner et al., 2018; Carter et al., 2007).

The findings from this study highlight a demand to improve the current structure of coordinated care for children with CCN. Stakeholders in this study felt they needed more support in their role when providing care for complex patients. Having to handle their professional scope of practice, while simultaneously acting as a source of knowledge for their patients' other medical and social needs, became a challenge. Poorly defined roles can become a source of conflict and confusion in care settings (Baker & Denis., 2011; Brault et al., 2014; Nelson et al., 2014).

Interview participants emphasized the lack of collaboration among care providers of

children with CCN. Nuyen et al. (2019) addresses the importance of teams encompassing a range of interprofessional providers for improving the quality of care and outcomes for this population. Brenner et al. (2018) found that it is not possible for only one specialist or professional to possess all the knowledge needed to provide high quality care for children with CCN; care providers must work together when delivering quality patientcentred care. A coordinated care approach would provide an opportunity for providers to work together and educate one another on each child's comprehensive needs (Brenner et al., 2018; D'Amour et al., 2005; Nzirawa, 2015; Vos et al., 2020; Zwarenstein & Reeves, 2006).

The complex needs of these children require professionals to collaborate, share knowledge, and work as a team. Implementing an interprofessional care approach would allow providers to communicate effectively regarding a patient's needs and how they can best care for their patient within their scope of practice (Brenner et al., 2018; D'Amour et al., 2005; Nelson et al., 2014; Zwarenstein & Reeves, 2006). Clear communication between care providers will reduce time wasted in organizing an effective care plan for patients, as well as improve the relationship between stakeholders and families.

According to stakeholder participants, another barrier to accessing care is privacy conflicts among providers and provinces. There is often a lack of continuity of information sharing among providers, which has been found to result in a reduction in collaboration among providers and a lack of timely access to services for children with CCN. Interview participants highlighted also the inconsistencies encountered when trying to access patient information quickly. Technology can be used to improve the current challenges providers have when trying to communicate. Electronic health records and charting systems have been shown to support coordination and communication among health providers. Electronic health records in hospitals have led to a decrease in duration of time spent in the hospital, increased patient satisfaction with the care provided, and



a decreased number of readmissions (Vos et al., 2020; Wani & Malhotra, 2018). This demonstrates that the use of integrated care plans could improve both the care of children with CCN and the collaboration and sharing of information among providers (Brenner et al., 2018; Vos et al., 2020; Wani & Malhotra, 2018).

Problems between providers directly affect the patients and their care needs. The need for providers to put the well-being of the patient first is crucial in developing effective plans for children with CCN. Participants discussed the stress that caregivers of children with CCN felt when constantly repeating their child's history and having to be a "walking" medical record. Caregivers in this study expressed that valuable time was wasted in appointments by having to reiterate information that could be provided to stakeholders before the time of an appointment (Brenner et al., 2018; Charlton et al., 2017; Samwell, 2012). Implementing medical record systems to facilitate easy and secure access to clients' medical history is one way to lessen the extra burden placed on caregivers (Vos et al., 2020; Wani & Malhotra, 2018).

At present, there are both gaps in and barriers to the resources and services available for caregivers of children with CCN. Caregivers may encounter systemic barriers obstructing their knowledge of existing resources, an issue that health-care providers do not always have the knowledge or expertise to counter, and once that information is provided to families it can be challenging for them to gain access to the resources. Improving the communication between the intersectoral team members will allow providers to better educate families on the current resources for children with CCN and how to access them (Brenner et al., 2017; Brenner et al., 2018; Charlton et al., 2017). Ensuring the intersectoral team is using evidence-based practices was a concern raised by caregivers during the interviews. Having care providers keep up to date on the latest research and best practice methods would also improve the current care model used for children with CCN (Brenner et al., 2018; Cohen et al., 2018; Looman et al., 2020). Caregiver participants

commented on their desire to be part of their child's care plan. Some felt they were never included in the planning and were not given the time they needed to understand and ask questions about their child's present and future care. Not allowing caregivers to be part of the planning of care could damage the trust of the provider-caregiver relationship. This mistrust can have a negative impact on the outcomes of the child (Baird et al., 2016; Brenner et al., 2018; Ward et al., 2015). The findings from this study reflect many of the six interprofessional competency domains outlined in the introduction. Incorporating interprofessional communication when providing care for patients allows the intersectoral team members to work together effectively. The results section discusses the many frustrations the intersectoral team has when providing care for children with CCN. Outlining responsibilities for each role allows providers to collaborate effectively and reduces conflicts that may arise between professionals. Providing patient/family-centred care ensures patients' values and needs guide all decisions strengthens the patient-provider and relationship. Moving forward, it is important to find ways to integrate these competencies into practice to improve the care being provided to children with CCN and their caregivers.

#### Limitations

This study was a qualitative study that drew on participants' perspectives and concerns about collaboration and communication among health workers who support children with CCN and their caregivers. This study does have some limitations. First, our findings focused on the needs and perspectives of those in NB and PE populations and therefore may not be transferable to other populations. Second, an interview approach was used where sampling bias could have occurred, and it may not be an accurate representation of the entire population and their perspectives. However, this study provided a strong initial assessment of interprofessional collaboration when caring for children with CCN populations in two Atlantic



Canadian provinces and is a starting point for future studies.

#### Conclusion

Findings from the study support the to improve collaboration between need providers and caregivers when caring for children with CCN. Reducing the current barriers to accessing information by utilizing consistent reporting systems, as well as improving the coordination of care through interprofessional collaboration developing practices, are a few ways to improve communication among the groups involved in this study. Providers need to focus on addressing patient and caregiver concerns to improve patient/family-centred care moving forward. Caregivers want to be included in the care plan of their child and have their concerns listened to. Implementing communication strategies to reduce the number of times a caregiver has to repeat their child's medical history will improve the provider-caregiver relationship. These key findings need to be considered when informing current and future policy improvements.

#### References

- Baird, J., Rehm, R. S., Hinds, P. S., Baggott, C., & Davies, B. (2016). Do you know my child? Continuity of nursing care in the pediatric intensive care unit. *Nursing Research*, 65(2), 142–150. https://doi.org/10.1097/nnr.00000000 00000135
- Baker, G. R., & Denis, J.-L. (2011, September). *A*comparative study of three

  transformative healthcare systems:

  Lessons for Canada. Canadian Health

  Services Research Foundation.

  https://www.cfhi-fcass.ca/sfdocs/default-source/commissionedresearch-reports/Baker-DenisEN.pdf?sfvrsn=0
- Barnert, E. S., Coller, R. J., Nelson, B. B., Thompson, L. R., Tran, J., Chan, V., Padilla, C., Klitzner, T. S., Szilagyi, M., &

- Chung, P. J. (2019). Key population outcomes for children with medical complexity: A systemic review. *Maternal and Child Health Journal*, *23*(9), 1167–1176. https://doi.org/10.1007/s10995-019-02752-1
- Boudreau, A. A., Goodman, E., Kurowski, D., Perrin, J. M., Cooley, W. C., & Kuhlthau, K. (2014). Care coordination and unmet specialty care among children with special health care needs. *Pediatrics*, 133(6), 1046–1053. https://doi.org/10.1542/peds.2013-2174
- Brault, I., Kilpatrick, K., D'Amour, D.,
  Contandriopoulos, D., Chouinard, V.,
  Dubois, C.-A., Perroux, M, & Beaulieu,
  M.-D. (2014). Role clarification
  processes for better integration of
  nurse practitioners into primary
  healthcare teams: A multiple-case
  study. *Nursing Research and Practice*,
  2014, Article 170514.
  https://doi.org/10.1155/2014/170514
- Braun,V., & Clarke,V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://psycnet.apa.org/doi/10.1191/1 478088706qp063oa
- Brehaut, J. C., & Kohen, D. E. (2016). Complexity as a continuum of many health-related challenges. *Developmental Medicine and Child Neurology*, *58*(11), 1099. https://doi.org/10.1111/dmcn.13238
- Brenner, M., Kidston, C., Hilliard, C., Coyne, I., Eustace-Cook, J., Doyle, C., Begley, T., & Barrett, M. J. (2018). Children's complex care needs: A systematic concept analysis of multidisciplinary language. *European Journal of Pediatrics, 177*(11), 1641–1652. https://doi.org/10.1007/s00431-018-3216-9
- Brenner, M., O'Shea, M., Larkin, P. J., Kamionka, S. L., Berry, J., Hiscock, H., Rigby, M., & Blair, M. (2017). Exploring integration of care for children living with complex care needs across the European Union



- and European economic area. *International Journal of Integrated Care,* 17(2), Article 1.
- http://doi.org/10.5334/ijic.2544
- Canadian Interprofessional Health
  Collaborative (2010, February). *A*National Interprofessional Competency
  Framework. http://ipcontherun.ca/wp-content/uploads/2014/06/National-Framework.pdf
- Carter, B., Cummings, J., & Cooper, L. (2007). An exploration of best practice in multiagency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of Clinical Nursing*, 16(3), 527–539. https://doi.org/10.1111/j.1365-2702.2006.01554.x
- Charlton, P., Azar, R., Luke, A., Doucet, S.,
  Montelpare, W., Nagel, D., Hyndman, N.,
  & Thompson, K. (2017). Falling through
  the cracks: Barriers to accessing
  services for children with complex
  health conditions and their families in
  New Brunswick. *Journal of New*Brunswick Studies, 8, 133–158.
  https://journals.lib.unb.ca/index.php/J
  NBS/article/view/25883
- Cohen, E., Berry, J. G., Sanders, L., Schor, E. L., & Wise, P. H. (2018). Status complexicus? The emergence of pediatric complex care. *Pediatrics*, 141(S3), S202–S211. https://doi.org/10.1542/peds.2017-1284E
- Cohen, E., Dennis, Z. K., Agrawal, R., Berry, J. G., Bhagat, S. K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, *127*(3), 529–538. https://doi.org/10.1542/peds.2010-0910
- D'Amour, D., Ferrada-Videla, M., San Martin Rodriguez, L., & Beaulieu, M.-D. (2005). The conceptual basis for interprofessional collaboration: Core concepts and theoretical frameworks.

- Journal of Interprofessional Care, 19(S1), 116–131. https://doi.org/10.1080/13561820500 082529
- Doucet, S., Nagel, D. A., Azar, R., Montelpare, W. J., Charlton, P., Hyndman, N., Luke, A., & Stoddard, R. (2017). A mixed-methods Quick Strike research protocol to learn about children with complex health conditions and their families.

  International Journal of Qualitative Methods, 16(1).

  https://doi.org/10.1177%2F16094069 17731426
- Looman, W. S., Park, Y. S., Gallagher, T. T., & Weinfurter, E. V. (2020). Outcomes research on children with medical complexity: A scoping review of gaps and opportunities. *Child: Care, Health and Development, 46*(1), 121–131. https://doi.org/10.1111/cch.12725
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1), 137–140. https://doi.org/10.1542/peds.102.1.13
- Nelson, S., Turnbull, J., Bainbridge L., Caulfield, T., Hudon, G., Kendel, D., Mowat, D., Nasmith, L., Postl, B., Shamian, J., & Sketris, I. (2014). *Optimizing scopes of practice: New models for a new health care system.* Canadian Academy of Health Sciences. https://cahs-acss.ca/wp-content/uploads/2015/07/Optimizing-Scopes-of-Practice\_REPORT-English.pdf
- Nuyen, B. A., Domogauer, J. D., Jennings, L., Kinzel, J., & Eliason, M. J. (2019). Interdisciplinary approach to care. In J. R. Lehman, K. Diaz, H. Ng, E. M. Petty, M. Thatikunta, & K. Eckstrand (Eds.), *The equal curriculum: The student and educator guide to LGBTQ health* (pp. 57–70). Springer. https://doi.org/10.1007/978-3-030-24025-7



- Nzirawa, T. (2015). Caring for children with complex needs. *Nursing Management*, 22(5), 32–38. https://doi.org/10.7748/nm.22.5.32.e1 390
- Pluye, P., Bessière, G., Bigras, M., Boulet, A., Brenner, K., Crist, E., Duong, S., Goulet, S., Granikov, V., Jean-Marie, M., Kayal, D., Kremer, B., Loignon, C., Martello, C., McLauchlin, L. R., Nguyen, Q., Omon, E., Rosenberg, E., & Grad, R. (2014). Characteristics of complex care needs and interventions suited for patients with such needs: a participatory scoping review [Poster presentation]. North American Primary Care Research Group (NAPCRG) Annual Conference, New York, United States. https://www.mcgill.ca/familymed/files /familymed/fmfnapcrg\_scopingposter\_ print.pdf
- Samwell, B. (2012). From hospital to home: Journey of a child with complex care needs. *Nursing Children and Young People*, 24(9),14–19. https://doi.org/10.7748/ncyp2012.11. 24.9.14.c9389
- Shimmura, K., & Tadaka, E. (2018).

  Development of an interprofessional collaboration competency scale for children with medical complexity. *BMJ Open*, 8(6), Article e019415.

  https://doi.org/10.1136/bmjopen-2017-019415
- Statistics Canada (2008). *Participation and activity limitation survey 2006: Families of children with disabilities in Canada*. https://www150.statcan.gc.ca/n1/pub/89-628-x/89-628-x2008009-eng.htm
- Stewart, M. A. (2018). Stuck in the middle: the impact of collaborative interprofessional communication on patient expectations. *Shoulder & Elbow, 10*(1), 66–72. https://doi.org/10.1177/17585732177 35325
- UNICEF. (2013, May). The state of the world's children 2013: Children with disabilities.

- https://www.unicef.org/media/84886/file/SOWC-2013.pdf
- Vos, J. F. J., Boonstra, A., Kooistra, A., Seelen, M., & van Offenbeek, M. (2020). The influence of electronic health record use on collaboration among medical specialties. *BMC Health Services Research*, 20, Article 676. https://doi.org/10.1186/s12913-020-05542-6
- Wani, D., & Malhotra, M. (2018). Does the meaningful use of electronic health records improve patient outcomes? *Journal of Operations Management*, 60(1), 1–18. https://doi.org/10.1016/j.jom.2018.06. 003
- Ward, C., Glass, N., & Ford, R. (2015) Care in the home for seriously ill children with complex needs: A narrative literature review. *Journal of Child Health Care*, 19(4), 524–531. https://doi.org/10.1177/13674935145 38327
- World Health Organization. (2011, December 14). World report on disability. https://www.who.int/publications/i/it em/world-report-on-disability
- Zwarenstein, M., & Reeves, S. (2006).

  Knowledge translation and interprofessional collaboration: Where the rubber of evidence-based care hits the road of teamwork. *The Journal of Continuing Education in the Health Professions*, 26(1), 46–54.

  https://doi.org/10.1002/chp.50



#### Research Protocol

# Bibliometric Analysis of Perinatal Anxiety and Depression from 1920-2020: A Protocol

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#### Abstract

Introduction: From pregnancy to the first year postpartum, both men and women experience significant physical, psychological, and social changes that may increase their risk of a mental illness, including anxiety and depression. There has been significant growth in the frequency of literature around anxiety and depression across the perinatal period over the past decades with variation in definition, measurement outcomes, and populations. To focus future research and identify gaps, it is important to explore patterns and trends in the current literature. **Objective:** The objective of this bibliometric analysis is to analyze the characteristics and trends in published research on anxiety and depression across the perinatal period from January 1, 1920 to the end of 2020. Inclusion criteria: All published literature in Web of Science on perinatal anxiety and depression from January 1, 1920 to December 31, 2020. Methods: Web of Science will be used to analyze bibliometric information through their built-in analysis feature and citation report that generates a list of leading publications, publication years, authors, source titles, countries/regions, organizations, and research areas. VOSviewer will be used to analyze and visualize the networks of linkages between the identified reports, including bibliometric networks, including co-authorship, co-occurrence, and cocitation, as well as co-occurrence between keywords. Conclusion: This study will provide useful information to guide future work on perinatal anxiety and depression. This bibliometric review will provide an overview of the work to date in perinatal mental health, identify key contributions to the field, and identify knowledge gaps and future directions.



# Bibliometric Analysis of Perinatal Anxiety and Depression from 1920-2020: A Protocol

#### Introduction

Throughout the perinatal period from pregnancy to the first year postpartum, mothers and fathers experience significant physical, psychological, and social changes that may increase their risk of a mental illness, including anxiety and depression (O'Hara & Wisner, 2014). Over the years, there has been a growth in literature on perinatal mental illness, and in 1994, postpartum depression was recognized in the Diagnostic and Statistical Manual (DSM-IV) as a Major Depressive Disorder with Postpartum Onset (American Psychiatric Association, 2013). While there is no specific recognition in the DSM-V of anxiety specific to the perinatal experience, anxiety in all populations is the most common mental illness diagnosed each year (Ströhle et al., 2018).

Perinatal depression is a non-psychotic depressive episode that begins in or extends from pregnancy into the postpartum period, ranging from minor depressive symptoms to a clinical diagnosis (Lanes et al., 2011). Symptoms can include anxiety, guilt, negative maternal attitudes and attachment, and poor parenting self-efficacy and coping skills, lasting up to 14 months postpartum (Lanes et al., 2011). While often comorbid with perinatal depression, perinatal anxiety is a separate mental health concern, shaped by fear and worry rather than depressive thoughts and can emerge as generalized anxiety, panic disorders, obsessive compulsive disorder, or post-traumatic stress disorder (Ali, 2018). Anxiety can manifest itself as several symptoms, including "excessive and persistent fear, worry, and tension and regularly includes physical symptoms such as sleeping difficulties and inability to concentrate. Severe symptoms include panic and recurrent intrusive thoughts or images, often related to the harm of their child" (Dennis et al., 2016, p. 486). While anxiety and depression may be pre-existing or may emerge in the antenatal period, studies have shown that it is important to reassess for possible anxiety and depression in the

postpartum period due to the changes that occur after birth and variation in symptoms across the perinatal period (Andersson et al., 2006; Bayrampour et al., 2016).

There has been significant growth in the literature around depression and anxiety across the perinatal period over the past decades, with significant variation in definition subsequent measurements of these mental health outcomes (Meades & Ayers, 2011; Sinesi et al., 2019; Ukatu et al., 2018) as well as coreported psychosocial outcomes (Leach et al., 2017; Norhayati et al., 2015; Wee et al., 2011). To focus future research and identify gaps, it is important to explore patterns and trends in the current literature. To do this, we will use a bibliometric analysis approach that seeks to comprehensively explore patterns in publications in a given research area, including trends over time and the influences of contributions by citations, such as relationships between authors and publications (Donthu et al., 2021; Gauthier, 1998). Bibliometric analysis has been used across a variety of academic disciplines to provide a broad overview of the current literature to provide description, evaluation, and scientific and technological monitoring (Donthu et al., 2021; Gauthier, 1998). While there have been many reviews on anxiety and depression across the perinatal period, none to date have used this approach to map the evolution of published literature on perinatal mental health to characterize research outputs, distribution, and relationships.

The objective of this bibliometric analysis is to analyze the characteristics and trends in published research on anxiety and depression across the perinatal period over the past hundred years, from January 1, 1920 to December 31, 2020. Specifically, this study aims to identify, analyze, and visualize research publications on perinatal anxiety and depression, exploring outcomes and relations such as author, country, institution, and year to provide an overview of perinatal mental health research over the last hundred years.



#### Methods

This study follows the standard bibliometric approach (Donthu et al., 2021; Gauthier, 1998; Linnenluecke et al., 2020), using the following steps: "(1) define the search criteria, keywords, and time periods; (2) selection of Web of Science database; (3) adjustment and refinement of research criteria; (4) full export of result; (5) analysis of the information and discussion of the results" (Ruiz-Real et al., 2018, p. 2).

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews, and PROSPERO was conducted, and no current or underway systematic reviews, scoping reviews, or bibliometric analyses on the topic were identified.

#### **Citation Database**

The search strategy will be conducted in Web of Science using the Web of Science Core Collection. This includes Science Citation Index Expanded (SCI-EXPANDED)—1900-present, Social Sciences Citation Index (SSCI)—1956-present, Arts & Humanities Citation Index (A&HCI)—1975-present, Conference Proceedings Citation Index- Science (CPCI-S)—1990-present, Conference Proceedings Citation Index- Social Science & Humanities (CPCI-SSH)—1990-present, and Emerging Sources Citation Index (ESCI)—2015-present.

The use of a singular database is recommended in bibliometric reviews and may vary depending on question of interest (Donthu et al., 2021; Ruiz-Real et al., 2018). For the purpose of this review, Web of Science was selected as the only database as it (1) has 90 million records from 256 disciplines from 1900 to present, representing a good breadth of relevant citations; (2) provides a summary report on key bibliometric outcomes, including publication, authors, and research areas; and (3) exports into a format that is required for analysis in the software tool VOSviewer (Moral-Muñoz et al., 2020). The authors ran the search in PubMed, Scopus, PsycInfo, and Web of Science, and found that Web of Science had the largest number of records identified, thus

solidifying it as the ideal sole database for this topic despite its potential limitations (e.g., citation counts may vary from other databases).

#### **Search Strategy**

The search strategy has been developed by leading experts in the perinatal mental health field (JD, MC-Y, C-LD, and PL-W) in consultation with a health science librarian using terms for postpartum depression and anxiety as used in the literature. Separate searches were developed for anxiety and depression and are available in Table 1.

#### **Inclusion and Exclusion Criteria**

Literature will be considered for inclusion when published since January 1, 1920 to December 31, 2020 in any language. The following exclusion criteria will be applied and the number of studies that were excluded will be identified in the full report:

- Records in 2021 will be excluded, as the records here would not have had time to be cited and it would create an incomplete picture in the timeline (as it only reflects a partial year of publications).
- Records must be classified as either an article or review, excluding conference abstracts, books/book reviews, and other non-peer reviewed material.

#### **Procedure**

Once the search is run, the outputs will be exported with all available information, including Full Records and Cited References, in ".txt" format, which will be used for the bibliometric analysis in VOSviewer, as well as ".csv" format. Due to limitations in Web of Science, reports will be downloaded in batches of 500 and merged into one singular file for analysis. Separate outputs will be created for bibliometric analysis related to perinatal anxiety and depression.



**Table 1**Search Strategy Used for the Bibliometric Review on Perinatal Anxiety and Depression

Topic	Search Strategy for Web of Science
Perinatal Anxiety	TS=((pregnan* OR perinatal* OR antenatal* OR postnatal* OR peripartum OR postpartum OR "post partum" OR "new mother*" OR "new father*" OR "new parent*" OR (after NEAR/2 birth*) OR paternal* OR maternal*) NEAR/3 (anxiet* OR anxious*)) Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=1920-2020
Perinatal Depression	TS=(((pregnan* OR perinatal* OR antenatal* OR postnatal* OR peripartum OR postpartum OR "post partum" OR "new mother*" OR "new father*" OR "new parent*" OR (after NEAR/2 birth*) OR paternal* OR maternal*) NEAR/3 (depressi*) OR "baby blues") Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI Timespan=1920-2020

#### **Data Analysis**

#### **Bibliometric Data**

Web of Science will be used to analyze bibliometric information through their built-in analysis feature and citation report, including authors' names and number of publications per author, countries (based on author affiliations) and number of publications per country, journals and number of publications per journal, publication type and number of publications by type, year and number of publications per year, and research area (defined by Web of Science) and number of publications per research area.

Additionally, the top 20 reports with the highest number of citations will be reported. Web of Science output files will be downloaded for analysis.

#### **Visualization Mapping**

VOSviewer is a software tool that was designed specifically for bibliometric reviews and can provide visual analysis based on bibliometric networks (Moral-Muñoz et al., 2020). It will be used to analyze and visualize the networks of linkages between the identified including bibliometric networks, reports, including co-authorship, co-occurrence, and cocitation, as well as co-occurrence between keywords (excluding non-relevant or generic terms; van Eck & Waltman, 2020). While networks can be generated using a variety of bibliographic database files (e.g., Web of Science, Scopus, PubMed, RIS, EndNote), data from reference managers cannot be used for some including identifying analysis. citation. bibliographic coupling, and co-citation links between items (van Eck & Waltman, 2020). Therefore, using the citation output directly from Web of Science provides the most effective option to produce visualization.

Maps are created using one type of item (i.e., reports, authors, terms) to explore links or connections with other items, with each link having a strength (van Eck & Waltman, 2020). For co-authorship links, for example, the strength of the link would be based on the number of publications two authors have coauthored (van Eck & Waltman, 2020). A network visualization map is composed of items (circles) and links (lines and closeness) together (van Eck & Waltman, 2020). Within the network there may exist clusters, which are grouped based on similarity, and items may only belong to one cluster (van Eck & Waltman, 2020). In addition, each item may have a weight, or score assigned to it, with higher weights/scores regarded as more important than lower, and these higher weights/scores are shown more notably on network maps by a larger circle (van Eck & Waltman, 2020). Also possible is overlap visualization, which is the same as network visualization but coloured differently based on



scores or user-defined colours, and density visualization, which is similar to network visualization but uses colour to indicate density of items at that point, with higher weights being more yellow and lower weights being more blue (van Eck & Waltman, 2020).

For the current review, visualizations will be created for co-authorship (of authors and countries), keyword co-occurrence, citation (number of times reports and authors cited together), bibliographic coupling (number of shared references for reports and authors), and co-authors (number of times references, sources, and first authors cited together). Additionally, co-occurrence of keywords will be conducted based on text data using title and abstract data. Prior to this, data cleaning will occur through the identification of similar words (e.g., same author but with first initial or all initials, behaviour/behavior) and exclusion of non-relevant terms (e.g., conclusion, method, result) by one reviewer, which will be managed through VOSviewer's thesaurus function.

#### Conclusion

This bibliometric review will provide insight into the publication trends in perinatal mental health over the past century, including identifying past (e.g., through co-citation analysis), present (e.g., bibliographic coupling), and future (e.g., co-word analysis) directions (Donthu et al., 2021). This bibliometric review will provide an overview of the work to date in perinatal mental health, identify key contributions to the field, and identify knowledge gaps and future directions.

#### References

Ali, E. (2018). Women's experiences with postpartum anxiety disorders: A narrative literature review.

International Journal of Women's Health, 10, 237–249.

https://doi.org/10.2147/IJWH.S15862

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.97 80890425596

Andersson, L., Sundström-Poromaa, I., Wulff, M., Åström, M., & Bixo, M. (2006).

Depression and anxiety during pregnancy and six months postpartum:

A follow-up study. *Acta Obstetricia et Gynecologica Scandinavica*, 85(8), 937–944.

https://doi.org/10.1080/00016340600697652

Bayrampour, H., Tomfohr, L., & Tough, S. (2016). Trajectories of perinatal depressive and anxiety symptoms in a community cohort. *Journal of Clinical Psychiatry*, 77(11), e1467–e1473. https://doi.org/10.4088/JCP.15m10176

Dennis, C.-L., Falah-Hassani, K., Brown, H. K., & Vigod, S. N. (2016). Identifying women at risk for postpartum anxiety: A prospective population-based study. *Acta Psychiatrica Scandinavica*, 134(6), 485–493.

https://doi.org/10.1111/acps.12648
Donthu, N., Kumar, S., Mukherjee, D., Pandey, N., & Lim, W. M. (2021). How to conduct a bibliometric analysis: An overview and guidelines. *Journal of Business Research*, 133, 285–296.
https://doi.org/10.1016/j.jbusres.2021.04.070

Gauthier, E. (1998). Bibliometric analysis of scientific and technological research: A user's guide to the methodology.

Statistics Canada.

https://www150.statcan.gc.ca/n1/en/pub/88f0006x/88f0006x1998008-eng.pdf?st=ejNrviqh

Lanes, A., Kuk, J. L., & Tamim, H. (2011).

Prevalence and characteristics of
Postpartum Depression
symptomatology among Canadian
women: A cross-sectional study. *BMC*Public Health, 11, Article 302.
https://doi.org/10.1186/1471-245811-302



- Leach, L. S., Poyser, C., & Fairweather-schmidt, K. (2017). Maternal perinatal anxiety: A review of prevalence and correlates. *Clinical Psychologist*, *21*(1), 4–19. https://doi.org/10.1111/cp.12058
- Linnenluecke, M. K., Marrone, M., & Singh, A. K. (2020). Conducting systematic literature reviews and bibliometric analyses. *Australian Journal of Management*, 45(2), 175–194. https://doi.org/10.1177/03128962198 77678
- Meades, R., & Ayers, S. (2011). Anxiety measures validated in perinatal populations: A systematic review. *Journal of Affective Disorders*, 133(1–2), 1–15. https://doi.org/10.1016/j.jad.2010.10.009
- Moral-Muñoz, J. A., Herrera-Viedma, E., Santisteban-Espejo, A., & Cobo, M. J. (2020). Software tools for conducting bibliometric analysis in science: An upto-date review. *Profesional de la Información*, 29(1), Article e290103. https://doi.org/10.3145/epi.2020.ene. 03
- Norhayati, M. N., Nik Hazlina, N. H., Asrenee, A. R., & Wan Emilin, W. M. A. (2015). Magnitude and risk factors for postpartum symptoms: A literature review. *Journal of Affective Disorders*, 175, 34–52. https://doi.org/10.1016/j.jad.2014.12.041
- O'Hara, M. W., & Wisner, K. L. (2014). Perinatal mental illness: Definition, description and aetiology. *Best Practice & Research: Clinical Obstetrics & Gynaecology, 28*(1), 3–12. https://doi.org/10.1016/j.bpobgyn.201 3.09.002
- Ruiz-Real, J. L., Uribe-Toril, J., Valenciano, J. D. P., & Gázquez-Abad, J. C. (2018). Worldwide research on circular economy and environment: A bibliometric analysis. *International Journal of Environmental Research and Public Health*, 15(12), Article 2699.

- https://doi.org/10.3390/ijerph151226 99
- Sinesi, A., Maxwell, M., O'Carroll, R., & Cheyne, H. (2019). Anxiety scales used in pregnancy: Systemic review. *BJPsych Open*, *5*(1), Article e5. https://doi.org/10.1192/bjo.2018.75
- Ströhle, A., Gensichen, J., & Domschke, K. (2018). The diagnosis and treatment of anxiety disorders. *Deutsches Ärzteblatt International*, *115*(37), 611–620. https://doi.org/10.3238/arztebl.2018.0 611
- Ukatu, N., Clare, C. A., & Brulja, M. (2018).

  Postpartum depression screening tools:
  A review. *Psychosomatics*, *59*(3), 211–219.

  https://doi.org/10.1016/j.psym.2017.11.005
- van Eck, N. J., & Waltman, L. (2020). *VOSviewer Manual version 1.6.16*. VOSviewer.

  https://www.vosviewer.com/download
  /f-33t2.pdf
- Wee, K. Y., Skouteris, H., Pier, C., Richardson, B., & Milgrom, J. (2011). Correlates of anteand postnatal depression in fathers: A systematic review. *Journal of Affective Disorders*, *130*(3), 358–377. https://doi.org/10.1016/j.jad.2010.06. 019



#### Research Protocol

# Community-Embedded Positive Mental Health Promotion Programs for the General Population: A Scoping Review Protocol

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#### **Abstract**

**Introduction:** Positive mental health promotion (PMHP) is an emerging field within community mental health. Programming and policy efforts devoted to promoting mental health are developing. These efforts are varied in scope and nature, and there is little consensus on evidence-based best practices. **Objective:** To chart the body of literature on PMHP programming and to document the current PMHP in one Canadian province to provide insight into the types, scope, and nature of the programs currently and historically available to community residents in this province. **Inclusion criteria:** Peer-reviewed literature relevant to community mental health promotion, and grey literature that contains details of community-based programs accessible to the general population in that community. **Methods:** A preliminary search strategy in PubMed, EBSCO, and PsycInfo was developed with a librarian and a JBI-trained researcher. Primary studies published in English after 2000 evaluating or documenting PMHPs will be included. Grey literature from an environmental scan of existing local programs will be included. Data to be extracted includes study methodology and methods, program scope, content, materials, evaluation and outcomes.

**Keywords:** mental health; community; health promotion; well-being; program implementation



#### Community-Embedded Positive Mental Health Promotion Programs for the General Population: A Scoping Review Protocol

#### Introduction

Positive mental health refers to a state of well-being that all individuals can achieve, regardless of whether they are experiencing mental illness, and is more than the absence of mental illness (Keves, 2006; Orpana et al., 2016). The complete definition of mental health includes both salutogenic (positive states of functioning and capacity) pathogenic (disease, disability, or premature death) perspectives (Keyes, 2013), and is characterized by high social, emotional and psychological functioning in everyday life (Keyes, 2002). As mental health is embedded within and influenced by a wider social, economic, and cultural ecology (Kobau et al., 2011), the determinants of positive mental health are inherently linked to the community in which one lives, works, and plays (Zubrick & Kovess-Masfety, 2005) Positive mental health is an individual resource, contributing to the individual's quality of life, and can be promoted within the community (Herman & Jané-Llopis, 2005). In the community, the act of promoting mental health seeks to strengthen individuals' psychosocial resources, enhance community institutions, and reduce structural barriers to positive mental health (Barry & Friedli, 2010; Herman & Jané-Llopis, 2005;).

Positive mental health promotion (PMHP) is an emerging field within community mental health. Community mental health is a system of care designed to reach specific populations of people in a way that is geographically accessible and locally relevant (i.e., program and services are tailored to the needs of the community; Caplan, 2013). It emphasizes the salutogenic perspective, suggesting that mental health is more than the absence of mental illness (Catalino & Fredrickson, 2011), and encompasses our wellbeing and level of functioning in everyday life. Programming and policy efforts devoted to promoting mental health are emerging. These efforts are varied in scope and nature, and there

is little consensus about which aspects of positive mental health to target, as well as unclear alignment with local health authority capacity. For example, community institutions such as schools, homes, work sites, places of worship, and health-care settings have been traditional targets for public health disease prevention and health promotion interventions, but are also promising settings for evidence-based PMHP interventions (Kobau et al., 2011).

Documenting PMHPs and related outcomes such as well-being can help in supporting and evaluating health promotion and public health wellness initiatives. A first step is charting the evidence base and identifying promising practices related to PMHPs that exist in communities. Reviews have been conducted with a focus on youth (Kuosmanen et al., 2019), and low-income countries (Barry et al., 2013), but, to date, the literature on community programs to promote *positive* mental health in non-clinical populations remains sparse. For example, a narrative review summarized PMHPs that were based in schools and designed for adolescents. finding that socio-emotional learning is a promising focus area for improving the mental health of young people (Kuosmanen et al., 2019). A systematic review focusing on vouth in low- and middle-income countries found that school-based interventions tend to be successful in improving self-esteem and coping skills, although results vary by gender and age (Barry et al., 2013). A gap in current knowledge is the characteristics of PMHPs offered in community settings to the general public. To chart the literature on PMHPs, we will review grey and peer-reviewed literature documenting the design and delivery of community-level PMHP programs. The grey literature will be documented through an environmental scan of existing programs available in the province (Nova Scotia). The peer-reviewed literature will be documented to chart the international body of literature describing PMHP programming.

A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis* was conducted, and no current or in-progress



scoping reviews or systematic reviews on the topic were identified.

The objective of this review is to chart the body of literature on PMHP programming and to document the current PMHPs in one Canadian province to provide insight into the types, scope, and nature of the programs currently and historically available community residents in this province. The context of mental and physical health in Nova Scotia includes low positive affect (e.g., happiness), and rates of chronic disease (e.g., chronic obstructive pulmonary disease) tend to be disproportionately high (Davidson et al., 2010). Conducting the environmental scan in one province is more feasible than conducting a national scan, and as all programs fall within one health authority (Nova Scotia Health), assessing the gap between current programs and international best practices will provide tangible recommendations aligned with the context of the province.

#### **Review Questions**

What is known about community-based PMHP programs for the general population?

Sub-question 1: What is the health-promoting content of existing PMHPs? (e.g., teaching life skills, empowering individuals to become mental health literate)?

Sub-question 2: What methodologies, methods, measures, and tools have been used to study, assess, and implement these programs?

Sub-question 3: What is the evidence base for these programs?

#### **Inclusion criteria**

#### **Participants**

This review will consider studies that document mental health promotion programming within the community, available to the general public, without requiring a physician referral or a previous diagnosis.

#### Concept

PMHP programming within a community may include programs that teach

basic life skills (e.g., emotion regulation, interpersonal communication), remove stigma related to mental health (e.g., improve mental health literacy), or guide individuals in therapeutic recreation or leisure activities such as personal projects, hobbies, or community interest group participation.

#### Context

This review is not limited to specific groups, places, or identities; rather, the review will consider all programs that are available to the general population. The environmental scan will be focused within a given geographical community, as explained previously.

#### **Types of Sources**

This scoping review will consider conceptual, quantitative, qualitative, and mixed methods study designs for inclusion. Systematic reviews and text and opinion papers will not considered for inclusion.

#### Methods

In consultation with a librarian and a Johanna Briggs Institute-trained researcher, a preliminary search strategy in PubMed, EBSCO, and PsycInfo was developed. The proposed scoping review will be conducted in accordance with the IBI methodology for scoping reviews (Peters et al., 2020). Scoping reviews address an exploratory research question by systematically searching, and selecting from, a wide range of literature to determine the breadth of evidence on a particular topic (Peters et al., 2020). Scoping reviews are designed to chart a body of literature with relevance to time, location, source, method, and origin (Levac et al., 2010). Our scoping review of peer-reviewed and grey literature will be complemented by an environmental scan of existing regional PMHP programs. Specifically, the scan of existing programs in Nova Scotia will provide baseline data on efforts by regional organizations and resources in the field of PMHP, identify gaps in evidence-based practices, summarize lessons learned, and identify challenges in the



implementation of programs and opportunities for the delivery of future PMHP programming.

#### **Search Strategy**

The search strategy will aim to locate both published and unpublished primary studies. An initial limited search of MEDLINE (PubMed) and PsycInfo (EBSCO) undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE and PsycInfo (see Appendix A). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. The reference lists of articles written by Margaret Barry (a pioneer of mental health promotion) will be screened for additional papers.

Articles published in English will be included, as our research team is limited to English speakers. Articles published from 2000 to the present will be included, as the evidence-based concept of PMHP emerged at this point in time. The databases to be searched include PsycInfo (EBSCO), MEDLINE (PubMed), Scopus, and CINAHL. Google Scholar will be used to identify grey and unpublished studies.

#### **Study/Source of Evidence Selection**

Following the search, all identified records will be collated and uploaded into Mendeley and duplicates removed. Following a pilot test, titles and abstracts will then be screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant papers will be retrieved in full, and their citation details imported into Covidence. The full text of selected citations will be assessed in detail against the inclusion criteria by independent reviewers. Reasons for exclusion of full-text papers 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 selection process will be resolved through discussion or with a third reviewer. The results

of the search will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) flow diagram (Tricco et al., 2018).

#### **Data Extraction**

Data will be extracted from papers included in the scoping review by two independent reviewers using a data extraction tool developed by the reviewers. The data extracted will include specific details about the mental health promoting content within the community program (e.g., the health-promoting skill or competency covered), the evidence base or theoretical background that the program is informed by, the methodologies, methods and measures that the program has been evaluated with, and the outcome of the program. A draft extraction tool is provided (see Appendix B). The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included paper. Modifications will be detailed in the full scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

#### **Data Charting and Presentation**

The data extracted from relevant published and unpublished literature will be displayed to include the author and year of publication, type of source, intervention content, population(s), materials used, and documented outcomes. Data extracted from included papers will be presented in a tabular form, and the table will report key findings relevant to the review question(s). Data will be charted based on types of health-promoting content (e.g., life skills, emotion regulation). Results will be categorized under program type. A narrative summary will accompany the tabulated data and will describe how the results relate to the review objective and question.



#### **Declarations**

#### **Ethics Approval and Consent to Participate**

This paper contains only publicly available information.

#### **Consent for Publication**

Not applicable.

#### **Availability of Data and Materials**

Data sharing is not applicable to this article as no data sets were generated or analyzed during the current study.

#### **Competing Interests**

The authors declare that they have no competing interests.

#### **Funding**

Not applicable.

#### Acknowledgements

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#### References

- Barry, M. M., Clarke, A. M., Jenkins, R., & Patel, V. (2013). A systematic review of the effectiveness of mental health promotion interventions for young people in low and middle income countries. *BMC Public Health*, 13, Article 835. https://doi.org/10.1186/1471-2458-13-835
- Barry, M., & Friedli, L. (2010). The influence of social, demographic and physical factors on positive mental health in children, adults and older people. In C. L. Cooper, J. Field, U. Goswami, R. Jenkins, & B. J. Sahakian (Eds.), *Mental capital and wellbeing* (pp. 475–484). John Wiley & Sons.
- Caplan, G. (Ed.) (2013). An approach to community mental health (1st ed., Vol. 3). Routledge. https://doi.org/10.4324/97813150138
- Catalino, L. I., & Fredrickson, B. L. (2011). A Tuesday in the life of a flourisher: The

- role of positive emotional reactivity in optimal mental health. *Emotion*, 11(4), 938–950.
- https://doi.org/10.1037/a0024889
  Davidson, K. W., Mostofsky, E., & Whang, W.
  (2010). Don't worry, be happy: Positive affect and reduced 10-year incident coronary heart disease: The Canadian Nova Scotia Health Survey. European Heart Journal, 31(9), 1065–1070.
  https://doi.org/10.1093/eurheartj/ehp 603
- Herman, H., & Jané-Llopis, E. (2005). Mental health promotion in public health. *Promotion & Education*, *12*(S2), 42–47. https://doi.org/10.1177/10253823050 120020107
- Keyes, C. L. M. (2002). The mental health continuum: From languishing to flourishing in life. *Journal of Health and Social Behavior*, 43(2), 207–222. https://doi.org/10.2307/3090197
- Keyes, C. L. M. (2006). Mental health in adolescence: Is America's youth flourishing? *American Journal of Orthopsychiatry*, 76(3), 395–402. https://doi.org/10.1037/0002-9432.76.3.395
- Keyes, C. L. M. (2007). Promoting and protecting mental health as flourishing: A complementary strategy for improving national mental health. *American Psychologist*, 62(2), 95–108. https://doi.org/10.1037/0003-066x.62.2.95
- Keyes, C. L. M. (Ed.) (2013). *Mental well-being: International contributions to the study of positive mental health*. Springer. https://doi.org/10.1007/978-94-007-5195-8
- Kobau, R., Seligman, M. E. P., Peterson, C.,
  Diener, E., Zack, M. M., Chapman, D., &
  Thompson, W. (2011). Mental health
  promotion in public health:
  Perspectives and strategies from
  positive psychology. *American Journal*of Public Health, 101(8), e1–e9.
  https://doi.org/10.2105/ajph.2010.300
  083



- Kuosmanen, T., Clarke, A. M., & Barry, M. M. (2019). Promoting adolescents' mental health and wellbeing: Evidence synthesis. *Journal of Public Mental Health*, *18*(1), 73–83. https://doi.org/10.1108/jpmh-07-2018-0036
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, *5*, Article 69. https://doi.org/10.1186/1748-5908-5-69
- Orpana, H., Vachon, J., Dykxhoorn, J., McRae, L., & Jayaraman, G. (2016). Monitoring positive mental health and its determinants in Canada: The development of the Positive Mental Health Surveillance Indicator Framework. Health Promotion and Chronic Disease Prevention in Canada, 36(1), 1–10. https://doi.org/10.24095/hpcdp.36.1.0
- Peters, M. D. J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2020) Chapter 11: Scoping Reviews. In E. Aromataris & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis*. JBI.
- Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473. https://doi.org/10.7326/m18-0850
- Zubrick, S. R., & Kovess-Masfety, V. (2005).
  Chapter 12: Indicators of mental health.
  In H. Herrman, S. Saxena, & R. Moody
  (Eds.), Promoting mental health:
  Concepts, emerging evidence,
  practice (pp. 148–168). World Health
  Organisation.



### Infographic

# An Infographic Presenting the Types of Self-injurious Behaviours

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#### **Abstract**

To this day, there is immense confusion among clinicians and researchers on which behaviours fall under the rubric of self-injurious behaviours (SIBs) or on how to categorize them into meaningful groups (Simeon & Favazza, 2001). It was not until 2013, that Non-Suicidal Self Injury (NSSI) Disorder was included in the DSM 5 and recognized as a unique clinical entity (Gratz et al., 2015). Even so, SIBs have numerous jargons where the word 'self-harm', though most frequently used, is often confused with other related behaviours. The most essential condition of self-injurious behaviour whether suicidal or non-suicidal is that the self-harm or potential for self-harm itself is a deliberate consequence of the behaviour. Thus, it is distinct from acts that are dangerous but not undertaken with the motivation to inflict harm on oneself such as driving fast or drinking excessively and behaviours that are culturally and socially sanctioned such as tattoos, piercings or religious rituals. The present infographic is an overview of SIBs. It especially focuses on the various types of NSSI, in the order of increasing lethality. The three NSSI groups presented are mild, moderate, and severe, placed based on tissue damage, followed by examples and exclusions. Though the lists are not exhaustive, the purpose was to help distinguish between the various types of SIBs. The infographic is based on existing literature and classification systems and is aimed at presenting a quick and simple understanding of SIBs, particularly NSSI, that can be of interest to clinicians, researchers, and the general population

#### References

Crosby, A., Ortega, L., & Melanson, C. (2011).

Self-directed violence surveillance;
uniform definitions and recommended
data elements. Version 1.0. Atlanta
(GA): Centers for Disease Control and
Prevention, National Center for Injury
Prevention and Control.
https://stacks.cdc.gov/view/cdc/1199
7

Gratz, K. L., Dixon-Gordon, K. L., Chapman, A. L., & Tull, M. T. (2015). Diagnosis and characterization of DSM-5 non-suicidal self-injury disorder using the clinician-administered non suicidal self-injury disorder index. Assessment, 22(5), 527-

539. https://doi.org/ 10.1177/1073191114565878

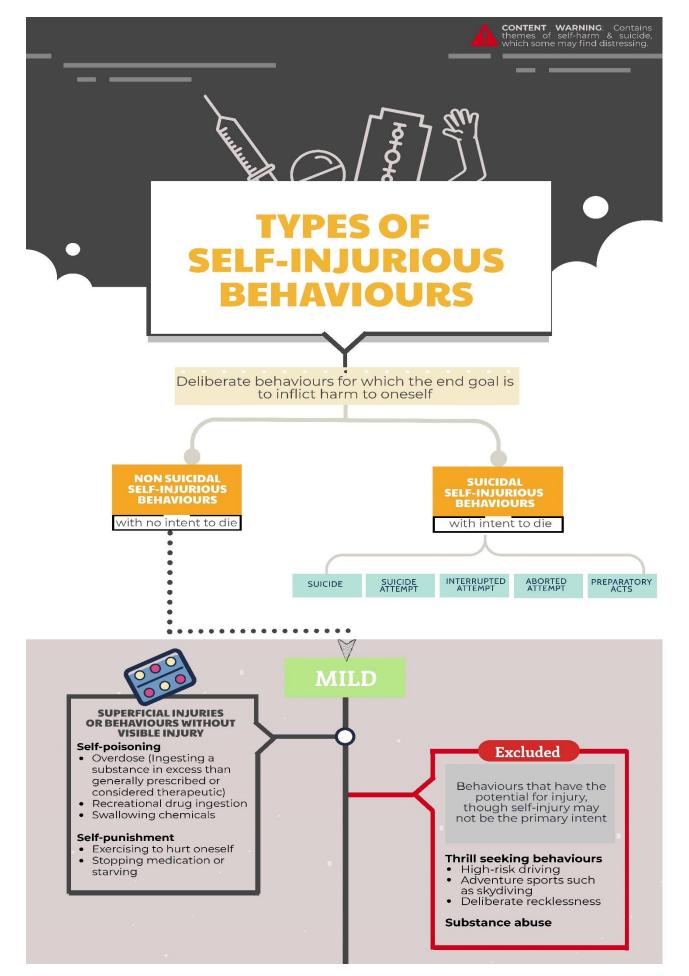
Khan, A., & Ungar, M. (in press). Resilience to self-harm: A scoping review of protective factors that aid in recovery among marginalized young people.

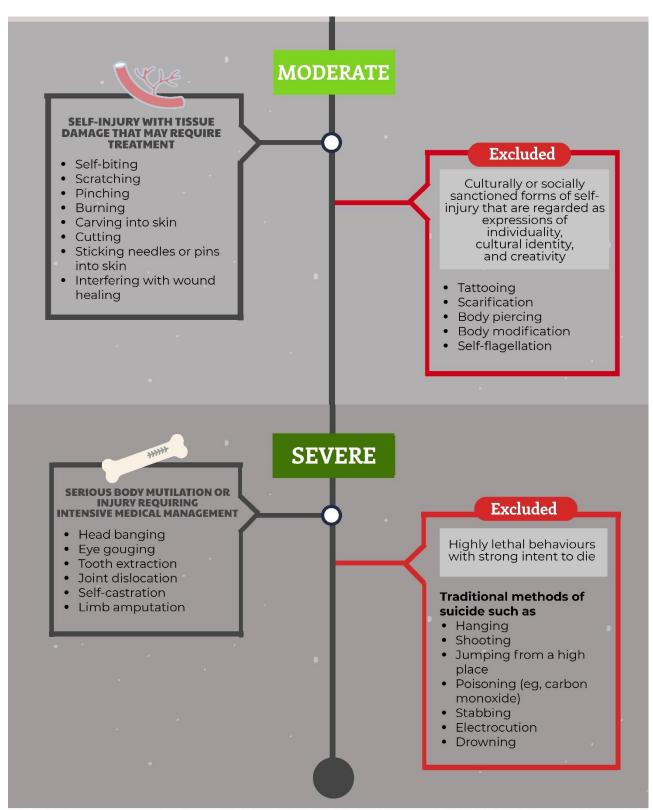
Crisis: The Journal of Crisis Intervention and Suicide Prevention

Nock, M. K. (Ed.). (2014). The Oxford handbook of suicide and self-injury. Oxford University Press.

Simeon, D., & Favazza, A. R. (2001). Self-injurious behaviors. Washington, DC.

Skegg, K. (2005). Self-harm. The Lancet, 366(9495), 1471-1483





Note: Various terms are used to refer to self-injurious behaviours (SIBs) such as non-suicidal self-injury, deliberate self-harm, self-directed violence, and self-mutilation, regardless of intent. Although the crucial distinction between suicidal and non-suicidal SIB hinges upon intent to die, Nock (2014) argues that issues in classifying intent itself may further pose difficulties in developing a widely accepted classification system. Therefore, such ambiguities in the conceptualization of the phenomenon lead to difficulty separating self-injury from culturally nuanced definitions of interrelated topics such as substance abuse, mental illness, and suicide (Khan & Ungar, in press).

Severity classification has been recognized as critical for surveillance, enidemiological investigations and evaluations of programs.

Severity classification has been recognized as critical for surveillance, epidemiological investigations and evaluations of programs and policies aimed at mitigating the impact of injury at both the individual and societal levels (Crosby et al., 2011). This infographic categorizes SIB based on injury severity which according to Crosby et al., (2011) is defined as the impact of an injury in terms of the extent of tissue damage and/or the physiologic response of the body to that damage.



### Infographic

# Infographic: Intimate Partner Violence Interventions Relevant to Women During the Covid-19 Pandemic

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#### **Abstract**

The COVID-19 pandemic has seen increased rates of intimate partner violence (IPV). This is attributed to greater stress on households and families (e.g., reduced income, limited access to childcare and schools), and isolation from friends and family. Public Health guidance on physical distancing and/or remote delivery of services are helpful for reducing the spread of infection, yet these restrictions can create further challenges and barriers for women seeking IPV services. In this review, we synthesized evidence from 4 systematic reviews and 20 individual studies to suggest how IPV services, supports, or interventions for women might be adapted within the context of the COVID-19 pandemic. Interventions generally fit into four main categories: 1) Preventing IPV through early recognition and awareness of IPV; 2) Counteracting abuse and breaking free; 3) Supporting women while living with and/or leaving an abusive partner; and 4) Supporting women after leaving an abusive partner. Many initiatives depend primarily on technology such as mobile phones and an internet connection for delivering information and interventions (e.g., mHealth, telehealth, websites, digital applications). However, it is important to consider that technological interventions are not available to all women given the financial resources necessary to secure a device and access to reliable internet. The results of this review can inform the service provision during the remainder of the COVID-19 pandemic and may be especially important for supporting women who have little access to face-to-face services (e.g., women living in rural and remote places where there are few inperson services).



#### References

- Abeid, M., Muganyizi, P., Mpembeni, R., Darj, E., & Axemo, P. (2015). A community-based intervention for improving health-seeking behavior among sexual violence survivors: A controlled before and after design study in rural Tanzania. *Global Health Action*, 8, Article 28608. https://doi.org/10.3402/gha.v8.28608
- Aromataris, E., Fernandez, R., Godfrey, C., Holly, C., Khalil, H., & Tungpunkom, P. (2020). Umbrella reviews. In E. Aromataris, & Z. Munn (Eds.), *JBI Manual for Evidence Synthesis*. Joanna Briggs Institute. https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-11
- Aromataris, E., & Munn, Z. (2020). *JBI Manual for Evidence Synthesis*. Joanna Briggs Institute, Adelaide, Australia. https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-20-01
- Bogart, N. (2020, May 3). Advocates scramble to help domestic violence abuse victims as calls skyrocket during COVID-19. CTV. https://www.ctvnews.ca/health/coron avirus/advocates-scramble-to-help-domestic-abuse-victims-as-calls-skyrocket-during-covid-19-1.4923109
- Enright, M. (2020, May 1). Calls are down to women's shelters during the pandemic, but it's not good news. The Sunday Edition, CBC Radio.
  https://www.cbc.ca/radio/sunday/thesunday-edition-for-may-3-2020-1.5547652/calls-are-down-to-womens-shelters-during-the-pandemic-but-it-s-not-good-news-1.5547818

- Ford-Gilboe, M., Varcoe, C., Scott-Storey, K., Perrin, N., Wuest, J., Wathen, C. N., Case, J., & Glass, N. (2020). Longitudinal impacts of an online safety and health intervention for women experiencing intimate partner violence: Randomized controlled trial. *BMC Public Health*, 20(1), Article 260. https://doi.org/10.1186/s12889-020-8152-8
- Khaki, L. (2016). Comparing the effectiveness of an interactive internet based safety-seeking decision aid for African American and white women in abusive relationships (Publication No. 10241710) [Doctoral dissertation, Morgan State University]. ProQuest Dissertations and Theses Global.
- McDonald J. & Green R. (2001). A dispersed refuge model for women escaping domestic violence: A regional case study. *Australian Journal of Primary Health*, 7(1), 85–89. https://doi.org/10.1071/PY01014
- World Health Organization. (2020). *COVID-19 and violence against women: What the health sector/system can do.*https://www.who.int/reproductiveheal
  th/publications/vaw-covid-19/en/



# INTIMATE PARTNER VIOLENCE INTERVENTIONS RELEVANT TO WOMEN DURING THE COVID-19 PANDEMIC



Stilwell, C., Weeks, L. E., Rothfus, M., Weeks, A., Macdonald, M., Jackson, L., Dupuis-Blanchard, S., Carson, A., Moody, E., Helpard, H., & Daclan, A. (2021)

Full article submitted to Violence Against Women Journal

#### THE ISSUE:

- Violence against women/intimate partner violence (IPV) often increases during emergencies like the COVID-19 pandemic
- Public health measures that aim to slow the spread of COVID-19 increases the time isolated at home with abusers
- Physical distancing, gathering limits, and closures can create barriers for accessing and providing IPV support





We conducted a systematic review of IPV services and interventions for women that are delivered in a way that meets COVID-19 public health guidelines

#### ABOUT THE IPV INTERVENTIONS INCLUDED IN THIS REVIEW:



Focused on preventing IPV from occurring.



Focused on identifying IPV, recognizing IPV, and tracking/sharing information about IPV incidents.



Focused on supporting women while living with and/or leaving an abusive partner.



Focused on supporting women after leaving an abusive partner.

A majority of studies described IPV interventions that were delivered using technology (i.e., mHealth, telehealth, online tools, forums, emails, apps, video or phone call, and radio)

#### **EXAMPLES OF RELEVANT IPV INTERVENTIONS:**



A violence/abuse awareness and education program transmitted via radio (Tanzania)



Identification and Referral to Improve Safety (IRIS), an internet-based IPV safety decision aid to flag abusive behaviours and assess safety options (USA)



iCanPlan4Safety online support tool to aid in risk assessment of an IPV situation and learn about options (Canada)



Marg's Place: an innovative emergency shelter model for women and children using separate smaller residences (Australia)



#### TECHNOLOGY IS GREAT! BUT...

- **SAFETY:** Preventive initiatives focused on digital literacy, competence, safety, and security are essential for women to be able to confidently access online resources
- **COST:** Digital/virtual devices and internet connectivity can be costly: Provide resources for women to access technology and devices
- **ACCESS:** Advocacy is needed to ensure the stability of communication networks, especially in rural or remote areas and in low-income countries
- **EFFECTIVENESS:** More research and evaluation is needed to measure outcomes and effects of current IPV services and supports
- **DIVERSITY:** IPV intervention studies must include diverse participants and an intersectional lens. Missing crucial data on: older women; women with disabilities, immigrant/refugee women, women in the LGBTQ+community, racialized women,...







#### INFORMATION SOURCES:

#### Our search found 24 sources that described a total of 238 interventions:

- 4 systematic reviews (n=218) from United States, Canada, and Germany
- 20 individual studies from United States (n=14), Canada (n=2), Australia (n=2), Hong Kong (n=1), and Tanzania (n=1)

A full description of our methods can be found in the forthcoming article or by contacting us

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Social Sciences and Humanities Research Council of Canada Conseil de recherches en sciences humaines du Canada











### Infographic

# Sustainable Healthy Diets: Food Swaps for Our Health & Our Planet

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#### **Abstract**

A healthy diet is important for our health, helping to reduce the risk of noncommunicable diseases and prevent malnutrition. Our diets and food choices can also have major impacts on the environment. Therefore, in thinking about healthy diets, we must also consider our planet. We can aim for diets that are healthy and diverse, with low environmental impacts. The Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO) has outlined guiding principles for the definition of "sustainable healthy diets". Based on these guiding principles, this infographic suggests food swaps that are beneficial both for our health and our planet, which can be used for the promotion of sustainable healthy diets.

#### References

FAO and WHO. (2019). Sustainable healthy diets – Guiding principles. Rome. https://www.who.int/publications/i/it em/9789241516648

WHO. (2018). Information sheet - A healthy diet sustainably produced. WHO. https://www.who.int/publications/i/it em/WHO-NMH-NHD-18.12



Food Swaps for Our Health & Our Planet

# SUSTAINABLE HEALTHY DIETS

Diets play an important role in our health. The foods that we eat can also have big impacts on our planet. We can help make a difference by choosing healthy, diverse foods that are produced and consumed in ways that reduces the environmental impacts of our diets. Based on recommendations from the Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO), check out the food swaps below for inspiration on sustainable healthy diets.

## **INSTEAD OF...**

### TRY...



#### **PROCESSED & RED MEATS**

Limit intake of processed & red meats. If eating seafood, pick sustainably sourced options whenever possible.



#### **PLANT-BASED FOODS**

If available, fill diet with locally grown vegetables & fruits. Try to choose plant-based proteins more often.



#### **HIGHLY PROCESSED FOODS**

When possible, avoid foods that are highly processed with lots of sugar or salt.



#### FRESH & HOMEMADE FOODS

If an option, cook more often. Buy foods that are in-season & local whenever possible.





#### SUGAR-SWEETENED DRINKS

When possible, avoid beverages with lots of added sugars. Limit fruit juice intake too.



#### **TAP WATER**

If safe, drink water from the tap. When possible, choose water over other beverages.







#### **OVEREATING**

Consuming excessive calories regularly can be harmful for personal health & the environment.



#### **EATING FOR ENERGY**

When possible, eat a variety of foods from all food groups to meet your energy needs.



#### TRANS FATS

When possible, avoid trans fats by reducing intake of processed foods, fast foods, & fried foods.



#### **UNSATURATED FATS & OILS**

If an option, use unsaturated fats in moderation. When possible, try to bake, boil, or steam your foods rather than fry.



#### **UNSAFE FOOD HANDLING**

Don't mix raw & cooked foods. Avoid storage at unsafe temperatures. Try your best to prevent food waste.



#### **HYGIENIC FOOD PRACTICES**

Always wash hands & sanitize surfaces before preparing foods.

#### REFERENCES:

1) FAO and WHO. (2019). Sustainable healthy diets – Guiding principles. Rome. https://www.who.int/publications/i/item/9789241516648
2) WHO. (2018). Information sheet - A healthy diet sustainably produced. WHO.

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### **Short Story**

### The Revival

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#### **About the Author**

Kevin is a 1st year PhD student at Trinity College Dublin researching the impact of microRNAs on the gut microbiome. Previously, he completed his MSc and BSc in Biochemistry at the University of Ottawa. He's an avid blogger, published fiction writer and host of the Metaphorigins Podcast. He's performed science communication pieces on national and regional platforms, and volunteers for science initiatives like Science Slam Canada and the Scholars Ireland Program for underrepresented youth.



#### **About the Story**

The Revival was written after a conversation with my brother about his experience as a gay youth in high school. This conversation, despite being difficult, permitted the both of us to reflect on society as it moves into a more progressive direction. The story itself is written in the style of American writer Shirley Jackson, attributed to genres of mystery, because of the lack of understanding towards sexuality and gender identity. One half of the story focuses on sexuality, while the other half highlights the burdens women have at all stages of their life. In the story, Jennifer is encouraged to remain at home rather than pursue a field in which women are underrepresented. Jennifer is also marginalized at her workplace by parents who do not reconcile her looks with societal archetypes of professionals in healthcare. Though changing, this experience is felt by women across the globe, and requires a cultural shift in not just acceptance, but awareness of where our own biases lie. The story assumes circumstances of mental health and suicide, concerns within people lost in this volatile system. Yet, until we address these concerns openly, cultural progress cannot be made.



#### The Revival

Good morning everyone.

Before the session begins, I would like to say a few words.

On behalf of John and Jennifer, I would like to thank you for attending this annual service. It would really mean the world to them to see you all here, in one place, despite the circumstances that brought us here today.

Today is the Revival. It is also the first time I have had the pleasure of meeting a vast majority of you. As their father, it saddens me that we only came together at such a time. However, based on our many conversations today, I can see why John and Jennifer have called you their extended family.

What I would like to do is to talk a little bit about the lives of these two extraordinary people in front of you. Perhaps, as we reflect collectively on the moments that were shared, this can give each of us a bit of closure, even a bit of *empathy*, so that we can understand my two favourite minds. Perhaps this may even allow us to reflect on our own lives and readjust, such that we can change the outcome of our own personal stories.

The happiest day of my life was when the twins were born. It's funny... The worst day of my life is also this same day, because the love of my life died giving birth to these very same twins. This was funny because life doesn't really prepare you for such a rare event, or any rare events for that matter. No, biased life seems to favour an archetype. And, coming from the average tall, white, straight man, you can believe me when I say that.

But I digressed. Any single, seemingly lonely parent will tell you that raising two newborns on your own is a feat equivalent to climbing an arduous mountain. Well, no expedition is complete without an experienced climber as their guide. That honorary title goes to my mother, Eleanor, who was the saving grace that helped take the twins from that *blank slate* to the magnificent people you all know.

I remember during their very first birthdays... It was so surreal to have many of you come dressed in blue and pink, their favourite colours. Let me tell you something... Another advantage of having twins is that you always get to have two cakes! A memorable moment, as many of you know, is John's face just covered in chocolate cake while Jennifer, clean as a whistle, slowly ate her vanilla cake sprinkled with colourful candies. The amount of trucks and dinosaurs, and dolls and tea sets now stacked away in my basement could put failing toy stores back in business!

Fast forward five years... Oh! Their first day of school. Do you remember that, Mom? How difficult it was to put them into their school uniforms. I think they gave John a pants size too big and Jennifer a dress size too small. Something was off, I'd say! And that entire car ride there was just full of groaning and complaining; longing for the lazy days, or concerned about meeting new people to make friends. Picking them up was such a contrast! John, just running, and I mean running, into the car. And then there was Jennifer, smiling while carrying her new textbooks. You can tell who had a good day and who just wanted to come home to their toys.

Let's jump ten years, to the end of high school. Everyone says that the teenage years are the worst years as a parent. They suddenly go from wanting you to wanting little to do with you. It was difficult. John was getting a football scholarship to Dalhousie University, and Jennifer was still a bit confused about what she wanted to do, where she wanted to go. She couldn't decide whether to go to Europe for an engineering degree or stay in town and do nursing. I wanted my baby girl close to my side, and eventually I ended up persuading her to go into nursing. Ultimately, I think she made the right choice, because she became the best goddamn nurse in the province.



Even though he was not the honour roll student, John did incredibly well through university, rising up the ranks of his football team and ending up being the star quarterback. He led his teams to win two consecutive championships, at the regional and finally the national level. It was at this point that I wish John had talked to me about his mental issues. Many of you probably know better than his old man, but John often denied his homosexuality, and his demeanour granted his fellow teammates ample opportunity for derision.

This was about the time when Jennifer started to... How do I put this... Change. I mean, back in her teenage years before the surgery, she would occasionally play in some punk band as their lead drummer. They called themselves "The Hirschfeld Committee", a strange name in my opinion. I asked her about it one day and she told me I needed to read up on my history. I tell you, when your kid replies with "read some history", sometimes all you can really do is laugh.

At this point, Mom was really worried. Her Catholic son had raised a gay son and an upcoming transgender daughter. Mom would say I was the "Founder of the LGBTQ Movement". I don't know why, but that comment stuck with me. I mean, Mom, was that supposed to be an insult? Even at work, I was being treated differently. For instance, the guys over at the plant were always talking about how sexy their wives are, how awesome their sons are in soccer or football, like John, or how adorable their daughters are in baking and dancing. You know, family stuff. Then I walk into the room, and immediately it became silent. And I mean silent. So silent, that I could almost hear their eyes staring at me. Nobody cared to ask how John and Jennifer were doing anymore. Why is that?

John finished his schooling in engineering and applied to his first job as an electrical engineer for Stonewall Solutions. Yes, our famous John - the Fashion Designer - was first an electrical engineer. Jennifer was also working as a nurse at the Pediatric Disability and Blood Management (PDBM) Hospital. Although she was the best goddamn nurse in the province, Jennifer later quit due to, and I quote, "inappropriate commentary by many of the children's parents". The twins hated this point in their lives. What was happening here? I couldn't figure it out and I was slowly going insane.

One night, six years after my twins were carelessly removed from this world, I was sitting at the dining room table with a glass of milk and took a sip. It had spoiled. After spitting it out in disgust I thought, "How do I know that this spoiled milk is bad for me"? I replied, "Well, because my body senses that I ingested something harmful and makes me spit it out". This experience, learned long ago, makes us remember that spoiled milk has a bad taste and texture. We label this type of milk as bad food.

Have you ever thought about how much we label things? How our brains categorize everything into specific groups? We do that with food, animals, cars, words and even people. We give people labels that describe their weight, their height, their personality. And all this seems strangely normal. So normal, in fact, we extend these labels beyond what they are meant for, extending them into our own personal lives. We label those who love the opposite sex as heterosexual and those who love the same sex as homosexual. Why did these words have different emotions attached to them? Why did heterosexuality seem average and bland while homosexuality seemed interesting and peculiar? Does this labelling not create majorities and minorities? And let's not get started on the inquisitiveness of, for example, a biological man who feels like a woman but is attracted to men...

Why do we need to label things anyway? It always comes down to human routine. A man walks into a room, sees a woman he likes, talks to her, dates her, marries her, has kids, etcetera. Obviously, life isn't as simple as that but realize that this is the normal story we were bombarded with throughout history. Who told us this was the only way of doing things? Why are we so accustomed to labelling this as the norm? Did the man even have a chance to decide that he likes women? Put even more broadly, what circumstances brought the woman to the room in the first place?



Let's look at John. John was born a boy. I raised him like anyone would raise a boy and encouraged him to like boy things. I rewarded boy behaviour. I overlooked any suggestion that John could think for himself and be curious about how a boy should grow up to be a man.

And what about Jennifer? Jennifer was born a girl. I cared for her like any father would care for their little girl. I recommended that she learn from close female role models like Mom. I clothed her like how most girls seemingly enjoy being clothed. I disregarded any notions that Jennifer could possibly be interested in the habits and activities that boys seemingly like to do.

That's just what we do. That's the only thing life prepares us for. Our society is unequipped to raise children any different than our ancestors did back in history. Can we remain this way? Would John and Jennifer have had a better life if they could choose how to live without outside influences? If we continue to be governed by people of the past, how could this possibly change?

For the Revival, we have voted to give John and Jennifer another chance to be a part of our *new* society. A society that has finally surpassed labelling our personal differences. A society apathetic to old romantic endeavours and primitive judgements about our capabilities to function in our gender roles. A society built on contributing to the goodness that life has to offer, and the freedom of personal development granted through equity and diversity. We have given them the hindsight of their future, and the wisdom that comes with it at an early age, so that they can decide to live the life they truly desire.

Back from the dead, please join me in welcoming my two favourite minds, John and Jennifer!

And as the congregation stood and applauded, there was a loud electrical shock that signalled the start of the re-animator. In less than 30 seconds, the two decomposing bodies at the front of the room shrunk down to healthy, intelligent adolescents.



#### THANK YOU!

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