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Review

Indigenous Women's Perspectives on Heart Health and Well-being: A Scoping Review

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ABSTRACT

Indigenous women tend to have higher rates of cardiovascular disease and/or stroke (CVD/s) and are less likely to report their health as good or excellent, in comparison to indigenous men. Cultural values and lived experiences of indigenous women can inform the relationship between them and their healthcare provider and their approaches to self-management of CVD/s. Health research often neglects to consider the subjective and cultural nature of health and well-being. A scoping review was conducted to identify available literature regarding indigenous women's perspectives on heart health. The research question for this scoping review was as follows: How do indigenous women who are at risk of and/or living with cardiovascular disease and stroke perceive their heart health and well-being? Database searches generated 4757 results, with an additional 37 articles identified from

RÉSUMÉ

Les femmes autochtones ont tendance à présenter des taux plus élevés de maladies cardiovasculaires et/ou d'accidents vasculaires cérébraux (MCV/AVC) et sont moins susceptibles de déclarer que leur santé est bonne ou excellente comparativement aux hommes autochtones. Les valeurs culturelles et le vécu de ces femmes peuvent influer sur la relation entre elles et leur professionnel de la santé ainsi que sur les modalités d'autoprise en charge des MCV/AVC. La recherche en santé fait souvent abstraction de la nature subjective et culturelle de la santé et du bien-être. Une revue exploratoire des publications abordant les points de vue des femmes autochtones en matière de santé cardiaque a été réalisée. La question d'intérêt était la suivante : Comment les femmes autochtones qui risquent d'être atteintes ou qui sont atteintes de maladies cardiovasculaires ou bien

Traditionally, indigenous women have been central to the health and well-being of their families and communities, taking on prominent roles as nurturers and leaders. ^{1,2} Colonial legacies, however, have perpetuated structural inequities, land displacement, and the silencing of female narratives, leading to negative health outcomes and a lack of access to health services. ² The effects of colonization have transcended into all aspects of indigenous peoples' health and well-being, on physical, mental, emotional, and spiritual levels. ³ Inequities are most pronounced for indigenous women, who tend to have higher rates of chronic disease and are less likely to report their health as excellent or good, in comparison with indigenous men. ⁴ A similarly elevated burden of disease for

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Ethics Statement: Though this scoping review did not necessitate a formal ethics review process, the Mending Broken Hearts project has received approval through the Hamilton Integrated Research Ethics Board and adheres to its ethical guidelines.

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See page 52 for disclosure information.

cardiovascular disease and stroke (CVD/s) has been observed in indigenous populations across the globe, with indigenous women in Australia being twice as likely as nonindigenous women to die from CVD/s.⁵

The Heart and Stroke Foundation of Canada advises that a gap exists between men and women in terms of CVD/s diagnosis, treatment, health promotion, and research, along with a lack of support and resources targeted to women's heart health. Further, the literature indicates that indigenous women experience heart-related illnesses more frequently and at a younger age than do nonindigenous women. Monchalin and Monchalin emphasize that factors contributing to these disparities in diagnosis, treatment, and prevention are complex and interconnected. This situation is due partly to differences in exposure to protective and risk factors and structural inequities in the healthcare system, including barriers to culturally responsive CVD/s treatment as a result of existing colonial legacies.

This review is a preliminary component of the "Understanding & Mending 'Broken' Hearts: Linking European Colonization, Indigenous Women's Heart Health, and Resiliency-Focused Approaches to Health Literacy" (MBH) project, led by Dr Bernice Downey. The MBH project is conducted in partnership with the following 3 community

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grey-literature depositories. A total of 378 articles were assigned a full-text review, of which 10 articles met the criteria for this analysis. The available literature provided evidence on how lifestyle, gender roles, relationships, mental and emotional health, health literature, culture, ceremony and healing, and experiences in the healthcare system impact the perspective that indigenous women have on heart health. Despite this population being at high risk for heart-related illnesses, indigenous women's perspectives on cardiovascular health and well-being continue to be underrepresented in the literature, warranting the need for culturally appropriate health policies informed by their lived experiences.

partners: De dwa da dehs nye > s Aboriginal Health Centre (an urban community); The Mississaugas of the Credit First Nation (an on-reserve community); and Lake St. Martin First Nation (an on-reserve community). This project has received funding from the Heart and Stroke Foundation (# 2000010800) and the Canadian Institute for Health Research (# 001-2000010800). The MBH project seeks to understand indigenous women's and community perspectives on heart health and well-being. Participants in this project include indigenous women, traditional practitioners, community members, and organizational representatives who work with indigenous women living with CVD/s. Although these participants were not directly included in this review process, the findings from this review will be shared and discussed within our project advisory committee, and with our community partners. Our expectation is that what we learn will support indigenous women's ability to self-manage their CVD/s more effectively.

The objective of this scoping review was to identify and summarize the existing body of literature on indigenous women's perspectives on heart health and well-being. An overarching goal of this project is to inform the future development of culturally safe prevention and management strategies for CVD/s.

Methods

Study inclusion criteria

Population. Articles were included for review if the study population identified as being indigenous women. Articles were not restricted by age group, in order to be inclusive of the perspectives of both indigenous women and girls. Articles that reported on both indigenous men and indigenous women were included if they provided data specific to women's experiences.

CVD/s outcomes. For the purposes of this review, the term "CVD/s" encompasses, but is not limited to, coronary artery disease (angina, myocardial infarction), stroke, heart failure, rheumatic heart disease, ischemic heart disease, cardiometabolic disorders, hypertensive heart disease, and peripheral artery disease. CVD/s risk factors, including hypertension, hypercholesterolemia, and dyslipidemia, were

qui risquent de subir ou qui ont subi un AVC perçoivent-elles leur santé cardiaque et leur bien-être? Les recherches effectuées dans des bases de données ont produit 4 757 résultats, et 37 articles supplémentaires ont été recensés dans des dépôts de littérature grise. Au total, 378 articles ont fait l'objet d'une recherche en texte intégral; de ce nombre, seulement 10 satisfaisaient aux critères d'analyse et comportaient des données probantes sur la façon dont le mode de vie, le rôle selon le sexe, les relations, la santé mentale et émotionnelle, les publications sur la santé, la culture, les cérémonies de spiritualité et de guérison ainsi que les expériences vécues au sein du système de santé influent sur le point de vue des femmes autochtones en matière de santé cardiaque. Même si les femmes autochtones présentent un risque élevé de maladies cardiaques, leurs points de vue en matière de santé cardiovasculaire et de bien-être continuent d'être sous-représentés dans les publications. Dans ce contexte, des politiques de santé en phase avec la culture et la réalité de ces femmes s'avèrent nécessaires.

also considered. Health behaviours, including physical activity, diet, smoking, and alcohol consumption, and comorbidities such as obesity and diabetes mellitus were considered in relation to CVD/s.

Study design, publication status, and language. All study designs were considered eligible, including experimental (randomized controlled trials), observational (cross-sectional, case studies, prospective, retrospective), secondary analyses, and qualitative. Study protocols, conference abstracts, opinion pieces, and editorials were excluded. Systematic and scoping review articles were also excluded. We searched peer-reviewed and grey literature sources for relevant articles. As a part of this grey literature review, indigenous-led health-related Web sites were reviewed. Only articles published in English were eligible for this review.

Study framework

A scoping review of both peer-reviewed and grey literature was conducted. This review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR) and was informed by the framework of Arksey and O'Malley.⁷

The methodology consisted of 5 stages: (i) identifying the research question; (ii) identifying relevant studies; (iii) selecting the studies; (iv) charting the data; and (v) collating, summarizing, and reporting the results.

Step 1: Identifying the research question. The research question for this scoping review was as follows: How do indigenous women who are at risk of and/or living with cardiovascular disease and stroke perceive their heart health and well-being?

Step 2: Identifying relevant studies. The search strategy for this systematic review was created in consultation with a health sciences librarian, and a sample can be found in Supplemental Table S1. After relevant search and index terms were identified and refined, searches were carried out on January 28, 2021 in the following scholarly databases: MEDLINE (Ovid; 1946-present); Emcare (Ovid; 1995 to

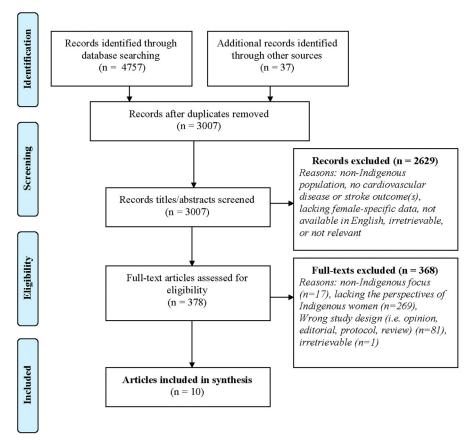


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

2021); HealthStar (Ovid; 1996 to January 2021); Web of Science; Informit Indigenous Collection; University of Saskatchewan Indigenous Studies Portal (iPortal); AnthroSource; and Sociological Abstracts. No restrictions were placed on the publication dates of articles. This step was designed to be inclusive of all pertinent literature and to demonstrate how the literature related to indigenous women's heart health has evolved over time. A scan of the grey literature included a search of the following sources: ProQuest Dissertations & Theses Global (1957-present) on April 16, 2021; Canadian Public Documents Collection on April 22, 2021; and Google Scholar on January 12, 2021. An advanced Google search of indigenous health-focused Web sites (most of which are indigenous-led or -informed resources) was conducted using the search strategy and Web sites outlined in Supplemental Table S2. Scoping and systematic review articles were not included in this review, but "backward snowballing" of articles took place, which entailed searching through the reference lists of relevant review articles that were identified during the search, for any articles that had potential to fit the research scope.8 Lastly, a standard Google Scholar search was conducted, using key terms also found in Supplemental Table S2, in which a single reviewer (Z.G.) inspected and screened the first 3 pages of results for relevant articles and screened the subsequent 3 pages when relevant results were found, until no more relevant results were in sight.

Step 3: Selecting the studies. Results from the database searches, with citations as outlined in Figure 1, were imported into a reference manager (Zotero, Corporation for Digital Scholarship, Fairfax, VA), and duplicates were manually deleted. Citations were then exported to a Microsoft Excel (Microsoft, Redmond, WA) template developed for screening. One reviewer (Z.G.) independently screened the title and abstract of all articles to identify potentially relevant articles.

Full texts of all articles meeting the inclusion criteria were obtained and reviewed independently by 2 reviewers (Z.G. and D.H.) using the screening software Rayyan (Qatar Foundation for Education, Cambridge, MA). Following the blind full-text review, the authors met to discuss and resolve any discrepancies and to finalize the number of included articles (n = 10).

Step 4: Charting the data. A standardized data extraction template was developed to evaluate each article and identify all relevant information. The following preliminary data were summarized and extracted from the included articles: author(s); year of publication; study country; study objectives; a summary of study methods; participants; cardiovascular outcome(s); conceptualization of gender; and sample size. Upon in-depth review and cross-examination of the articles, emerging themes, arguments, and perspectives of the articles were recorded and categorized accordingly.

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Step 5: Collating, summarizing, and reporting the results. The data charted in Step 4 were summarized in tables before a thematic analysis was conducted. The authors collectively reviewed the extracted data, organized the findings into relevant themes, and resolved any discrepancies through discussion.

Results

As reported in Figure 1, the database searches as described above generated 4757 results. An additional 37 results were identified in grey-literature outlets. After removing duplicates, 3007 results proceeded to title and abstract screening, and the results were then narrowed to 378. After full-text screening, 369 articles failed to meet eligibility criteria, for the following reasons: not being indigenous focused (n=17); lacking perspectives of indigenous women (n=270); having an ineligible study design, such as opinion pieces, editorials, study protocols, and reviews (n=81); and being irretrievable (n=1). A total of 10 articles met the inclusion criteria, and these were advanced to the data extraction step to be included in this scoping review.

Eligible article characteristics

The 10 eligible articles were published between the years 2005 and 2021, and they focused on indigenous populations from Canada (n=6), the US (n=2), and Australia (n=2). The populations within these articles identified as being Aboriginal and/or Torres Strait Islander (n=2), American Indian (n=2), First Nations and/or Métis (n=4), and indigenous (n=2). Included articles followed a qualitative (n=8) or mixed-methods (n=2) study design. A summary of the study objectives, study methods, population characteristics, and sample sizes of included articles can be found in Supplemental Table S3.

Findings from thematic analysis

The data extracted from this search was organized by emerging themes, which included: lifestyle, gender roles, relationships, mental and emotional health, understanding of heart health and health literacy, culture, ceremony and healing, and experiences in the healthcare system.

Lifestyle

Diet, exercise, and smoking. Of the 10 articles, 8 directly discussed the connection between lifestyle—including the impacts of diet, exercise, and smoking—and indigenous women's cardiovascular health. 9-16 Lifestyle factors identified by women as having a positive influence on one's health included eating a healthy diet, drinking water, being physically active, managing weight, having hobbies, and having good sleeping habits. In contrast, an "unhealthy life" was described as being related to the consumption of processed foods, being overweight, living a sedentary lifestyle, using drugs, and gambling. Although many indigenous women participants in these studies expressed the importance of consuming a diet high in whole grains, proteins, fresh fruit, and vegetables, they also identified that highly processed and sugary foods were the most affordable—and sometimes the only—option. 9,14 With regard to healthy eating habits,

researchers identified additional factors affecting lifestyle choices, including the following: living alone, lacking motivation to cook for oneself, and social pressures from family and friends to participate in social gatherings involving unhealthy foods. ^{13,15,17} Several articles highlighted the impact of indigenous culture on women's lifestyle behaviours, with having food at the centre of many social settings being considered a barrier to controlling diet. ^{13,15,16}

Smoking was identified by the women as having a negative impact on their heart health and increasing the risk of comorbidities. Many study participants expressed interest in quitting smoking, but reported that social environments encouraging smoking behaviour made it challenging. Additional barriers to smoking cessation were fears related to physical and psychological responses to quitting: stress, overeating, having a harder time because of partners who smoke, and the cost of nicotine replacement therapy. ^{15,16}

Impacts of colonialism on lifestyle changes. Colonial interferences on lifestyle were identified by study participants as affecting their heart health, and that of indigenous peoples more broadly.^{9,10} Indigenous peoples' ancestors were hunters, gatherers, and fishermen who lived off the land and followed traditional practices, such as gathering food and water. 10 In a study by Conklin et al., participants mentioned that hunting moose and foraging for berries were the traditional food practices of their ancestors, who as a result did not suffer from chronic diseases.¹² These practices provided a healthy life, in contrast to contemporary times in which access to junk food is common and more affordable than healthier options and traditional foods. 10 Food was described by participants in several articles as having medicinal properties and was considered integral to healing. Additionally, a shift from traditional, active lifestyles to more sedentary ones resulted in negative impacts on heart health. 10,12,16 For example, one participant described traditional living as quite physical, with living off the land, hunting and gathering, and travelling by canoe being traditional activities that kept both the body and mind active. 10

Articles in this review discuss the impacts of colonialism on the uptake of behavioural changes for managing heart health and well-being. Resistance to lifestyle changes was connected to residential school experiences in which Eurocentric lifestyle activities were forced upon many indigenous peoples as a tool of systematic manipulation and control. One participant attributed her resistance to lifestyle changes to her negative experiences in residential schools, where she experienced psychological manipulation to the point that she could not distinguish her own thoughts. Some of the women in the study noted that they resented people telling them what to do, and found the introduction of heart-healthy lifestyle activities to be intrusive. Women further expressed that these sentiments are rooted in colonialism, as generations of colonizers have attempted to dictate the lives of indigenous peoples.

Harsh economic realities facing many indigenous women have created additional barriers to healthy lifestyle changes. Globally, indigenous communities face disproportionately higher rates of unemployment, leading to increased difficulty with making the costly dietary lifestyle changes deemed necessary by healthcare providers (HCPs) to prevent and manage CVD/s. 11

Gender roles and expectations

Burden of caregiving. Another common theme was the integral role of indigenous women to the family structure, and how roles and responsibilities can influence the way that CVD/s manifests. In 5 of the articles, researchers explicitly report on the caregiving roles that women often take on throughout their lives and the burdens they can impose through stress, time, energy availability, and self-care. ^{10-12,15,16} For example, Medved et al. found that many women experienced the stress and distress associated with having responsibility for other people (caregiving) and noted a lack of adequate support and appreciation for this work. ¹¹

Family as a protective factor. In contrast, women also described those who depended on them, such as husbands, grand-children, and friends, as being a protective factor against developing heart problems. 11 Being nurturers in the family was important to indigenous women and contributed to feelings of love, connectedness, belonging, and identity. 11 Therefore, the responsibility of caring for family was identified as a key driver for looking after their heart health in the long-term. Some women also noted that during periods of illness or duress, family members would assume responsibility for household duties, either on an ongoing basis, or in the case of more acute events, until the women were again able to manage them. 16

Impacts of colonialism on gender roles. In the context of the traumatizing impact of residential schools, some women described a fear of putting oneself first as a woman and of having one's children taken away by social workers if they were to put themselves first. This fear that indigenous women face was said to negatively impact their ability to care for their own well-being and fostered social isolation. Indigenous women who survived the residential schooling system also attributed deteriorating heart health to the forced separation from their community, family, and the land, which caused considerable stress and grief.

Relationships. The theme of relationships was prominent across 5 articles, encompassing connectedness with oneself, family, community, and nation. McBride et al. stated that, for indigenous women, a strong identification with culture, family, community, and the environment provided a sense of connectedness, belonging, and love. Staying connected to community and having a support system of friends and family were identified as important factors for indigenous women's heart health, and family was considered essential to self-care. Women noted that reconnecting or strengthening relationships with their children and grandchildren was a route to healing their heart. 10 Downey found that relationships within the community serve as supportive networks and sources of health information, a primary resource for indigenous peoples managing their heart health and well-being. 18 Relationships with younger generations were also identified as facilitators of engagement in physical activity as a heart-healthy activity. 10,12

Mental and emotional health. Indigenous women reported that mental and emotional health and well-being were related to CVD/s in 5 of the articles. For example, changes that

affected their emotional health impacted their cardiovascular health as well. ^{9,11,14-16} Mental illnesses, including anxiety and depression, were further associated with CVD/s. Medved et al. found that many of the heart-health stories shared by indigenous women described anxiety as causing weak hearts, which then further perpetuated anxiety. ¹¹ Sources of stress identified by women ranged from multiple health issues, to challenges with family and community, financial hardship, racism, and discrimination. ⁹

Impacts of colonialism on mental and emotional health.

Multiple articles emphasized stress, grief, and trauma as influential factors causing a spiritual and physical breakdown of the heart. They discussed the impact of personal losses as causing indigenous women to have "heart sickness," indicating that trauma manifests in disease because the heart is broken. Traumas experienced by indigenous women included losing parents and grandparents at a young age due to being in residential school. Further, being forced to internalize emotions of anger, fear, and rage was another source of heart sickness, because residential school staff did not allow indigenous children to express emotion.

Understanding of heart health and health literacy. Across 5 of the articles, indigenous women identified a need to better understand their heart and how to take care of it. 9,11,13,14,19 As identified by Jones et al., women who shared their knowledge and understandings of health related to CVD/s were found to have opinions that were influenced and shaped by their interactions and experiences with others (often family members) who faced similar burdens of heart disease. 13 One woman from this study felt she had a greater chance of acquiring a heart illness because of her genetics—her father had a premature heart attack and her mother had heart problems early in life—whereas other women felt that they had a low risk of heart disease if no one in their family had any forms of CVD/s. 13 Familial history of sickness, including cancer, diabetes, heart disease, and stroke, was commonly associated with a perception of increased risk for CVD/s. 9,11,13,14

Indigenous women's self-identified knowledge of risk factors and symptoms of CVD/s varied across the articles. Some women had a good understanding of stroke symptoms but did not feel confident in their ability to identify signs of a heart attack, owing to a lack of information on the warning signs. On the other hand, some women said that the first sign of heart disease for them was experiencing a heart attack. In Medved et al.'s work, women described living in a chronic state of fear, not sure whether symptoms such as a racing heart were the result of anxiety, a heart attack, or both.

Only one study reported that participants displayed a high degree of knowledge of CVD/s risk factors, including an awareness of the role that physical activity, diet, cholesterol, and family history plays in risk for CVD/s. ¹³ Some women expressed uncertainty and a lack of knowledge about preventing heart illness in general. ¹⁴ Overall, researchers found that many women were surprised to learn that they had developed heart problems. ^{11,13,19}

Medved et al. found that participants did not mention whether symptoms were different for Aboriginal women, compared with those of non-Aboriginal people. 11 When women were asked about how they understood the discrepancy between the high rates of CVD/s in their family and community in contrast to those in the general public, many hesitated and had difficulty explaining this inconsistency. Rheumatic heart disease (RHD) has a high prevalence in Aboriginal women in Australia, yet it is not well understood by participants or their families, despite the fact that most women receive this diagnosis during childhood. 19 Belton et al. found that few participants knew that environmental factors had an influence on RHD, particularly poor housing conditions, and many were unsure if RHD was a serious illness. 19 Many Aboriginal women expressed the belief that RHD had unknown or supernatural causes and could be passed down to family members. 19 For example, one participant said that her aunt would repeatedly tell her that if she was sick or died, the sickness would also be passed down to the next generation in her family. 19 Some women also described smoking cessation, exercising more, and eating fewer fatty foods as ways to manage their RHD, confusing it with ischemic heart disease.1

Culture, ceremony, and healing. The sharing of traditional knowledge about healthy living and ceremony were described as integral factors for preserving the health of indigenous women and their communities. 12,15,18 Downey found that women reported an interest in learning more about their indigenous heritage or utilizing indigenous knowledge and healing approaches to address health issues. 18 Ziabakhsh et al. found that women identified culture as key for health promotion and acknowledged a cultural void in their own lives and communities. 15 Further, women referred to "culture as prevention," stating that an important connection to make is that between where women come from and their health and ability to get through tough times. 15 However, this cultural connection is not always accessible for indigenous populations who are living off-reserve, as many of them have lost access to their culture through colonial teachings. 15 With regard to traditional healing, some women reported that they turned to traditional teachings and practices to understand and cope with their heart problems. 11 An important component of healing that was identified was incorporating traditional practices, such as harvesting traditional medicines, performing spiritual ceremonies, and talking to spirits and ancestors. 11,18

Experiences in the healthcare system. A lack of culturally safe care was repeatedly mentioned in indigenous women's experiences of mainstream healthcare in 4 of the included articles. ^{10,12,14,19} Indigenous women frequently described mistreatment and racism experienced as a result of HCPs making assumptions about drug and alcohol use as the cause of illness in the absence of an accurate medical assessment. ¹² In one instance, Fontaine et al. interviewed a participant who said a relative was turned away from accessing healthcare due to the HCP's belief that nothing was wrong other than alcohol abuse. ¹⁰ Many of the women interviewed by Fontaine et al. also shared that they felt their medicines, ways of knowing, and worldviews were invalidated by HCPs and the healthcare system. ¹⁰ Women found that their primary care centres were not accommodating of the specific needs of indigenous

women, and in some cases, did not permit patients to bring in traditional foods or perform traditional healing practices. ^{12,19} Sanguins noted that, typically, HCPs approach indigenous peoples living with CVD/s as needing clinical and behavioural interventions but fail to consider the value and trust they may have in traditional healing practices. ¹⁶

Transportation to and from healthcare centres also challenged indigenous women's ability to receive adequate cardiac care. Travelling long distances between primary health centres and regional hospitals resulted in long periods of time away from home. Women also described the potential for seeking care far from home to be unsafe, especially if they were discharged during the night. 13,18

Sanguins found that participants' willingness to access westernized healthcare services was influenced by previous experiences within the system. Those who had poor experiences in walk-in clinics or an emergency department found that it resulted in delayed diagnosis or care, making them reluctant to seek out services again. Having discriminatory experiences with HCPs also increased participants' reluctance to access services, thereby further delaying CVD/s treatment. Sanguins found that mistrust in the healthcare system also stemmed from legends telling that the Opaskwayak Cree Nation People had been experimented on as a product of colonization. For example, stories of the organs of indigenous peoples being taken and used for another person were shared within the community and contributed to an increased reluctance to access healthcare services.

Relationship with healthcare providers. A recurring theme in 4 articles was the relationship between indigenous women and their HCP, and its effect on caring for their heart health. 12,16,19,18 Belton et al. found that language barriers were an issue in communication between Australian Aboriginal women and their HCPs, as the HCPs spoke formal English laced with medical jargon, and the women spoke Aboriginal English, which is recognized as being linguistically different. 19 None of the women who experienced language barriers in the study were offered interpreters during their clinical encounters, meaning that the health services provided were unsafe and lacked informed consent. 19 This degree of suboptimal communication resulted in many Aboriginal women feeling disengaged from their healthcare. 19 Additionally, Conklin et al. found that some women who had a heart attack or were diagnosed with heart problems indicated that their doctors did not effectively communicate strategies on how to live with and manage the disease, and that this lack of knowledge contributed to the women's fear about their health status.1

In some cases, women identified that caring and respectful relationships with their HCPs enabled them to "live well" with heart illness. ^{16,18} The degree of trust that indigenous women had in their relationship with their HCP was strongly influenced, both positively and negatively, by previous experiences. ^{12,16,19}

Facilitators of cardiac care for indigenous women. In 3 of the articles, women identified potential facilitators of care that they would like to see incorporated into successful hearthealth promotion programs. ¹⁴⁻¹⁶ Indigenous women

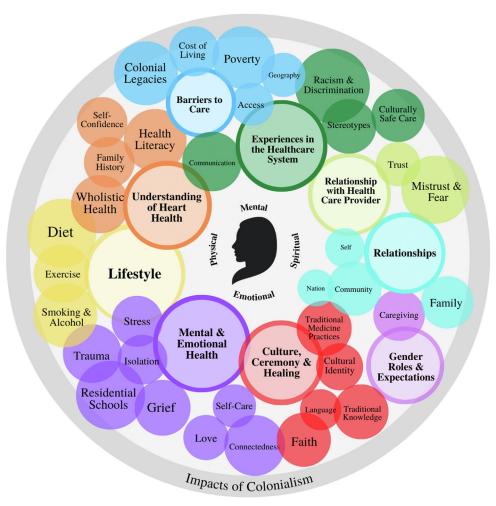


Figure 2. Visual depiction of the intersecting factors that have an impact on indigenous women's perspectives on heart health and well-being.

expressed that an ideal lifestyle program would provide motivation and promote accountability, while also accommodating the competing demands of family and work that women often experience.¹⁴ Effective program delivery, according to participants, would encompass a sense of social support and encourage family participation. 14,16 Extending education programs over longer periods of time would ideally provide maximum benefits to women and positively impact their ability to "live well." Moreover, the integration of cultural elements was highly valued by women participating in health promotion programs. 15 Ziabakhsh et al. also reported that women-only groups felt safer to participants for sharing and discussing sensitive issues and fostered a sense of community and connectedness to one another, as many were going through similar challenges. 15 Participants expressed the belief that the peer-support approach to managing CVD/s was empowering because the flow of knowledge was reciprocal and the discussions were inspiring. 15 Jones et al. found that the introduction of technology, including the option to opt-in to programs that use text-messaging to provide support or facilitate online sessions with a life coach, was suggested by participants as a potential solution to accommodate the busy lives of indigenous women. 14 Other means of facilitation that were identified by participants included the role modelling of

healthy behaviours in the family, social support, nutritional education, and access to activity-related services that offered childcare (Figure 2).¹⁴

Evaluation of engagement of indigenous peoples in health research

Incorporation of indigenous methodologies and ways of knowing into research is a crucial component of generating results that are both meaningful and genuinely representative of the perspectives of indigenous participants. Providing context when reporting on indigenous health outcomes is necessary to avoid perpetuating stigma and researcher bias.²⁰ To effectively assess the level of engagement of indigenous people within each of the included articles, the framework for indigenous engagement in health research developed by Hyett et al. was employed in this review. 20 Considerations for successful engagement in indigenous health research included the following: historical context, present-day context, ethical guidelines and protocols, indigenous methods and methodologies, community-based research, deficit- vs-strength-based research, and research allyship.²⁰ Specifically, the framework of Hyett et al. defines historical context as whether authors took the initiative to develop relationships and learn about the history of indigenous health research, and it defines present-

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day context as whether authors engaged indigenous scholars, organizations, and communities in every stage of the project.²⁰ Evaluation of the included articles revealed that 5 of them did not make an explicit effort to explore historical context, but a total of 9 articles did provide present-day context. All of the included articles did provide information on the ethical guidelines that informed their research to varying extents, and many researchers (n = 8) incorporated indigenous methodologies into their practice. Communitybased research was defined as ways in which research methods could restore ownership, power, and control to indigenous peoples. In this review, although all of the included articles focused on amplifying indigenous women's perspectives, only half (n = 5) discussed whether they integrated community perspectives into the research design at any or all stages.

A deficit- vs strength-based approach was a marker for whether research had the potential to stigmatize the indigenous community, and whether it acknowledged strengths, talents, and skills of the community. Lastly, research allyship entailed assessing whether researchers developed relationships with indigenous people to whom they were held accountable. A detailed assessment of each of the included articles, which met these criteria, with respect to the categories mentioned above can be found in Supplemental Table S4.

Significance of Findings

Traditionally, heart health for indigenous women was viewed wholistically—considering the physical, emotional, and spiritual dimensions of health within the context of one's family, community, and nation. Lifestyle has been shown to play a significant role in CVD/s manifestation, but the many disruptions to traditional ways of living and healing, as a result of colonization, are evident, as conveyed by the perspectives of indigenous women across the included articles. In accordance with our findings, Vallesi et al. reported that in Australia, colonization prompted a major shift away from a traditional diet and hunter-gatherer lifestyles and facilitated exposure to alcohol.²¹ The disproportionate burden of CVD/s for indigenous populations can be attributed generally to the loss of indigenous identity and family, and collective trauma experienced from residential schools that were put in place by colonization.²¹

Health disparities between indigenous and nonindigenous people continue to grow in Canada and globally, despite an expanding body of health research that attempts to address these inequalities. Among 378 full-text articles from our search of the literature that reported on indigenous peoples' heart health, we found that only 10 included the perspectives of indigenous women. Although biometric data add to the classification of rates and risk factors of CVD/s, little research has been done on the unique set of risk factors that matter most to the heart health of indigenous women, which can be identified by attending to their lived experiences. ¹²

Sanguins notes a continued lack of understanding of the cultural perspectives that First Nations Peoples have about CVD/s. Although the biophysiological processes of CVD/s are well documented in First Nations communities, the experiences of how First Nations Peoples "live well" with CVD/s have not been well investigated, ¹⁶ and as this review has

found, they continue to be under-investigated since Sanguins' 2006 findings. A point to note is that, in response to poor data practices, including the conceptualization of data items and reporting of data about indigenous people, an "indigenous data sovereignty" movement has emerged. Indigenous data sovereignty is described as "grounded in indigenous understandings of sovereignty that challenge dominant data sovereignty discourse and current practice" and is supported by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).²²

Half of the articles included in this review (n = 5) linked mental and emotional health to CVD/s outcomes in participants' experiences. In a supporting study by Ong and Weeramanthri, researchers found that stress and worry were perceived as a direct cause of heart disease that made managing heart health more difficult. 23 This finding complements the notion that emotional and mental health are linked to CVD/s outcomes, as identified in this review. Further, chronic stress paired with a perceived lack of control over one's thoughts and actions has been linked to poor health outcomes. 23

Gender roles and expectations for indigenous women was another recurring theme among half of the included articles (n = 5). Common barriers to preventive behaviours were linked to gender roles and expectations, including competing priorities, exhaustion, childcare and caregiver duties, and financial and geographic constraints. 10-12,15,16 A recent Australian-based study by McBride et al. notes that in addition to such barriers, current health programs and services available to women are rarely based on family and community approaches, and they ultimately fail to build on the role of women within society. Women's responsibilities within their family and community structures can make it difficult to access health services; therefore, developing services that are flexible to the needs of women is important. 11,13,16,17,21 Structural changes to services can include CVD/s rehabilitation programs that are offered at home, or at multiple geographic locations, and during a variety of times, to accommodate the schedules of indigenous women. Given that distance poses a barrier to accessing health services, and the potential for indigenous women to be unavailable during standard hours for health programs and appointments, telehealth is suggested by McBride et al., as a means to deliver timely care and improve health outcomes.

With regard to indigenous women's understanding of their heart health and health literacy, a clear finding from this review is that many indigenous women are unaware that they are at an elevated risk for CVD/s. According to McBride et al., the primary contact for women seeking information on how to reduce their risk for CVD is their HCP. Clear, 2-way communication between an HCP and a patient is important to enable the patient to make informed decisions regarding their health. Otherwise, having a limited understanding of one's heart health can affect decisions related to seeking care and can exacerbate cardiac conditions.²⁴ Many patients expressed the belief that they do not need to seek health services following major cardiac events, a view perpetuated by a lack of cardiac education and suboptimal communication between HCPs and patients.²⁴ Therefore, improving health literacy approaches should be a top priority for all healthcare systems, and this goal can be achieved by reducing the

complexity and barriers in accessing health services, as well as supporting educational programs that provide resources free of charge. Strategies to improve language barriers and knowledge gaps, for example, could include the introduction of interpreters and culturally relevant resources to create a safer environment for patients. Additionally, efforts to improve health literacy among American Indians in the US found that culturally relevant public education campaigns developed in consultation with tribal partners increased awareness of the warning signs of heart attack and stroke in American Indian communities. Assume that the provided resources are supported by the consultation with tribal partners increased awareness of the warning signs of heart attack and stroke in American Indian communities.

Findings from this review indicate that healthcare utilization for indigenous populations is shaped by experiences with the healthcare system and relationships with HCPs, further impacting health literacy. In a supporting study, Artuso et al. found that central Australian, Aboriginal, and Torres Strait Islander cardiac patients were likely to delay receiving care after a cardiac event due to intercultural communication challenges with HCPs. ²⁴ This finding supports an important subtheme in this review, particularly for Aboriginal women-—that HCPs' inability to speak local indigenous languages enhances patients' fear, as they were not familiar with what the HCP was saying and therefore could not make informed decisions.²⁴ This type of poor communication can happen when culturally safe services are unavailable, and it can lead to misinterpretation of critical health information on both sides.²⁴ An Australian report found that only 0.05% of doctors are Aboriginal women, posing a barrier to Aboriginal women who are seeking female practitioners and culturally appropriate health services.²⁶ Negative past experiences, language barriers, perceived racism, and a lack of cultural awareness from HCPs contribute to indigenous participants' mistrust in the healthcare system.²⁴ Trauma associated with residential schools, experimentation, and separation from family has led indigenous peoples, owing to mistrust of HCPs, to ascribe responsibility for high levels of CVD/s mortality to HCPmistreatment.²⁴ This mistrust was identified as being rooted in the dominance of the biomedical model that places a high degree of power into the hands of HCPs and takes away power from the patient.²⁴ Given that HCPs are often responsible for distributing appropriate knowledge, providing a diagnosis, and prescribing CVD/s medications, effective communication strategies are essential to support the selfmanagement approaches for indigenous women living with or at risk for CVD/s.2

HCPs need to be aware that incorporating indigenous people's perspectives ultimately contributes to improving health outcomes. ²⁸ Listening to the stories of participants may assist HCPs in the identification of crucial aspects of health relating to cultural values and beliefs, undiagnosed symptoms, and past experiences that could support culturally safe continuity models of cardiac care throughout a patient's journey to healing. ²⁸

Limitations

Although this scoping review aimed to be comprehensive, the results should be interpreted with consideration of the following limitations. First, the search strategy is limited in that not all indigenous communities across Canada, the US, and Australia were specifically included in the search string,

due to the fact that hundreds exist, and this lack of inclusion may have limited the perspectives captured. The search string was created using a biomedical approach to defining heart health and well-being, which may have narrowed the scope of the study and overlooked articles that define heart health and well-being using indigenous ways of knowing. Second, although all authors of the current study discussed and finalized the inclusion and exclusion criteria used, the final articles included, and the grey literature included in this review, a major limitation was that the title- and abstractscreening process was completed by one author (Z.G.), which influenced the fact that no Cohen's kappa score was obtained at this stage. In addition, no protocol was registered for this review. Further, the decision to include only English literature may have excluded relevant articles and research published in non-English-speaking countries or nations. Attempts to mitigate this limitation included the development of a search strategy for both the peer-reviewed and grey literature, in consultation with a health sciences librarian who had considerable experience working with indigenous literature

Indigenous women's voices were intended to provide the primary respondent perspective, and only literature that included data specific to indigenous women was included in this review. However, because research related to indigenous women's heart health is an emerging body of literature, some of the core themes identified in this review could be applied to both indigenous men and women; this could be considered limiting, as the objective was to focus on the experience of indigenous women specifically. In addition, the authors acknowledge that the health research community needs to create space for inclusion of indigenous voices with respect to their experience and knowledge. The scope for this review was to document the gap in the literature regarding indigenous women who experience CVD/s. Critical discussion to expand on the initial review goal and convey the implications of the women's perspectives in a way that reclaims and situates indigenous knowledge as important in relation to the health and well-being of indigenous women would ultimately strengthen this review. However, with this in mind, this important issue will be discussed in depth as part of the larger study findings for the MBH project.

Lastly, as is the case for most scoping reviews, an appraisal of the quality of the literature was not undertaken, ²⁹ which can be considered a general limitation of many scoping reviews, rather than a limitation of this specific review. However, as aforementioned, this review does evaluate the level of engagement of indigenous communities in each of the included articles, following the framework set by Hyett et al., as outlined in Supplemental Table S4. ²⁰

Conclusion

Indigenous women across the globe have been made vulnerable by the impacts of colonization, perpetuating sociocultural and socioeconomic risk factors for chronic diseases such as CVD/s. This review found that many indigenous women's perspectives on heart health and well-being included the influence of lifestyle habits, gender roles, relationships, emotional and mental health, and experiences with the healthcare system, with each of these being affected by the

lasting impacts of colonization. Factors often not considered within biomedical research, such as trauma, stress, and grief, have all been identified by indigenous women as contributors to their negative CVD/s outcomes. Residential schools have made an overall lasting negative impression on indigenous peoples collectively, contributing to much of that trauma and grief. Indigenous women described gender roles and expectations as impacting their ability to self-manage their heart illness, with the burden of caregiving contributing to stress and time spent away from self-care. Despite this population being at high risk for CVD/s, indigenous women's perspectives on cardiovascular health and well-being continue to be underrepresented in the literature. This significant gap warrants the need for culturally relevant research approaches and methodologies that prioritize and amplify the perspectives of indigenous women globally, to effectively influence policy, inform culturally safe healthcare practices, and improve health outcomes.

Researcher Positionality Statements

Dr Bernice Downey is a medical anthropologist and a former registered nurse. She is of mixed Ojibwe-Saulteaux/ Celtic ancestry, with kinship ties to Lake St. Martin and Dauphin River First Nations in Manitoba. Dr Downey's mother, Evelyn Desjarlais Downey McLaren, is Saulteaux/ Cree, was born in Lake St. Martin, and was raised in Dauphin River First Nation situated in Treaty 2 in Manitoba. Due to Canadian laws, Dr Downey was not able to identify as an "Indian" under the Indian Act and can list her status as being only a "non-status Indian." This term is known to indigenous people as denoting being of Canadian Indian descent but without having legal status as an Indian. Although Dr Downey is not able to legally recognize her indigenous heritage, and in spite of growing up in an urban environment, she maintains her indigenous identity through her family and the larger indigenous community. Dr Downey is engaged in a lifelong learning process of experiencing and understanding her Saulteaux culture and language. Dr Downey has invested most of her professional career working with indigenous peoples to help inform and mobilize self-determining approaches to health and research. She is the Associate Dean, Indigenous Health with the Faculty of Health Sciences at McMaster University in Hamilton, Ontario.

Dana Hart is a Research Officer in the Faculty of Nursing at the University of Toronto, and an anthropologist. Their background is Mi'Kmaq and settler with Newfoundlander roots

Zoya Gomes is a medical student enrolled at Dalhousie University and is currently residing in Halifax, Nova Scotia, in Mi'kma'ki, the ancestral and unceded territory of the Mi'kmaq People. Zoya identifies as a nonindigenous, woman of colour with settler roots. Zoya acknowledges that she is in a lifelong process of learning about the complex history of indigenous peoples, and is dedicated to practicing community-based, culturally safe research in the field of indigenous health and well-being. Zoya completed her MSc. Global Health at McMaster University under the supervision of Dr Bernice Downey, and she is assisting with the Mending Broken Hearts project.

The strategic priority of promoting and educating nonindigenous healthcare providers regarding indigenous cultural safety is responsive to the Truth and Reconciliation Commission of Canada's calls to action in their 2015 final report. This report is linked to one of the objectives of the Mending Broken Hearts project, which encompasses the training of healthcare providers to be more culturally responsive and safe when treating indigenous women with heart illness.

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Disclosures

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Supplementary Material

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