



Original Article

“Her Heart Matters”—Making Visible the Cardiac Pain Experiences of Women with Physical Disabilities and Heart Disease: A Qualitative Study

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ABSTRACT

Background: Women with physical disabilities are faced with challenges in many aspects of life—education, work, income, relationships, as well as their general health. These women are at a greater risk of developing heart disease. This study aimed to explore the cardiac pain experiences of women with physical disabilities and heart disease within a Canadian healthcare context.

RÉSUMÉ

Contexte : Les femmes qui présentent une incapacité physique doivent composer avec des défis dans de nombreux aspects de leur vie, notamment en ce qui touche l’éducation, le travail, le revenu, les relations et la santé en général. Le risque de cardiopathie est plus important dans leur cas. Cette étude visait à examiner comment la douleur cardiaque est vécue par les femmes présentant une

Women are more likely than men to develop severe or very severe disability over the course of their lives.¹ Disability is an umbrella term for impairment, activity limitation, and

participation restriction.² The 2012 Canadian Survey on Disability stated that more women than men lived with a disability in each of the provinces and territories in Canada, with the highest rates of disability reported in Manitoba, Ontario, and Atlantic Canada. Immigrant women aged 65 years and older had a higher prevalence of disability compared to non-immigrant women, and Indigenous women over 15 years of age were 1.5 times more likely to have a disability, compared with non-Indigenous women.³ A substantial number of women are living with a disability in Canada. In 2017, there were approximately 14.3 million women, compared to 13.6 million men, above the age of 15 years living with a disability.¹

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Methods: In this qualitative study, 8 women with physical disabilities and heart disease from across Canada were interviewed. They were asked about their pre-, peri-, and post-diagnostic experiences in the Canadian healthcare system. Transcripts of the interviews were analyzed using a hermeneutic phenomenological approach inspired by Ricoeur.

Results: Two main themes were uncovered in the analysis of the transcripts, as follows: (i) the diagnostic journey; and (ii) life with cardiac symptoms and a disability. The women indicated that they had experienced difficulties in utilizing the Canadian healthcare system prior to receiving a cardiac diagnosis, including long waitlists, expensive and unreliable transport, issues with accessibility, and dealing with providers' attitudinal barriers regarding disability. Receiving a diagnosis was challenging due to poor relationships with healthcare providers; however, having a same-sex provider seemed essential to receiving adequate care. Self-managing a disability and heart disease had significant physical and psychological impact, which was lightened by financial and social supports, modified lifestyle choices, and self-advocacy.

Conclusions: Women with physical disabilities are often forgotten in discussions encompassing equity and inclusion. The participants' experiences offer insight into what changes are needed within the Canadian healthcare system in order to improve outcomes for these women.

The leading cause of premature death for Canadian women is cardiovascular disease (ischemic heart disease [IHD], stroke, and heart failure).⁴ Heart disease (ie, IHD) in women is complex; it includes obstructive and non-obstructive coronary artery disease (CAD), varies across the lifespan,⁵ and is influenced by both sex and gender. Women's hearts and coronary arteries are smaller, and atherosclerotic plaque builds up differently in women's coronary arteries, compared with men's.⁶ The difference in plaque formation partly explains why early signs of IHD are missed in women. Results from the GENESIS-PRAXY (**Gender and Sex Determinants of Cardiovascular Disease: From Bench to Beyond Premature Acute Coronary Syndrome**) prospective cohort study suggest that gender is associated with higher rates of acute coronary syndrome (hazard ratio 4.50, 95% confidence interval [CI]: 1.05-19.27)⁷ and poorer access to care.⁸ Gender refers to socially constructed roles, behaviours, and expressions.⁹ Women have a varied pattern and distribution of cardiac pain and symptoms that make them difficult to interpret as being cardiac-specific.¹⁰⁻¹² Women also minimize their symptoms, prefer to consult with family and friends, and have caring responsibilities and concerns for their family.¹³ As a result, women delay seeking appropriate care for their cardiac pain and symptoms.¹⁴

Compared to people without disabilities, people with disabilities report higher rates of obesity, lack of physical activity, diabetes, and smoking, which are risk factors for CAD.^{15,16}

incapacité physique et une cardiopathie dans le contexte des soins de santé au Canada.

Méthodologie : Dans le cadre de cette étude qualitative, huit femmes présentant une incapacité physique et une cardiopathie ont participé à des entrevues menées à l'échelle du Canada. Elles ont été interrogées sur leurs expériences au sein du système de santé canadien au cours des périodes précédant, entourant et suivant le diagnostic. Les transcriptions des entrevues ont été analysées en fonction d'une approche phénoménologique herméneutique inspirée par Ricoeur.

Résultats : Deux grands thèmes ressortent de l'analyse des transcriptions, à savoir : (i) le parcours diagnostique; (ii) la vie avec des symptômes cardiaques et une incapacité physique. Les femmes interrogées ont indiqué qu'elles avaient éprouvé des difficultés dans leur parcours au sein du système de santé canadien avant de recevoir un diagnostic en cardiologie, évoquant à cet égard les longues listes d'attente, les services de transport coûteux et peu fiables, les problèmes d'accessibilité et les obstacles liés à l'attitude des fournisseurs de soins vis-à-vis de l'incapacité physique. Le fait de recevoir un diagnostic a été éprouvant en raison de rapports difficiles avec les fournisseurs de soins de santé; cependant, le fait d'avoir un fournisseur de soins de sexe féminin semblait être une condition essentielle à une prestation de soins adéquate. L'autoprise en charge d'une incapacité physique et d'une cardiopathie a eu des répercussions physiques et psychologiques importantes qui ont pu être allégées par le soutien financier et social, des modifications des habitudes de vie et l'autonomie sociale.

Conclusions : Les femmes qui présentent une incapacité physique sont souvent laissées pour compte dans les discussions portant sur l'équité et l'inclusion. Le vécu des participantes donne un aperçu des changements qui doivent être apportés au sein du système de santé canadien afin d'améliorer les résultats chez ces femmes.

Adjusted for age, women with physical disabilities in the US have 6.6 (95% CI: 5.2, 8.4) higher odds of having CAD, and 5.9 (95% CI: 4.3, 8.1) higher odds of having cardiac pain,¹⁷ and are less likely to receive preventive care,^{15,18} compared to women without disabilities. Women with disabilities report lower levels of educational attainment, workforce participation, and annual personal income. They are more likely to be single (odds ratio 1.37; 95% CI: 1.29, 1.46) or separated/divorced/widowed (odds ratio 1.47; 95% CI: 1.37, 1.59), compared to the general population.¹⁹ Thus, the effects of disability in women may pose a more serious risk for increased disease burden and adverse cardiac events, compared to the risk in women without disabilities. Nevertheless, there is an obvious lack of data exploring the cardiac pain experiences of women with disabilities and heart disease that may be contributing to poor outcomes in this population.¹⁸⁻²² Therefore, the purpose of this study is to explore the cardiac pain experiences of women with physical disabilities and heart disease within a Canadian healthcare context, using the gendered elements of disability, informed by Boyd's²¹ 6 steps to improve healthcare; these elements span micro (gender identity, gender roles [housework]), meso (gender relations [interactions between family, workplace, social networks]), and macro (institutionalized gender) levels.

Materials and Methods

A hermeneutic phenomenological qualitative study design was used, which allows for a detailed examination of lived

experiences, and of how individuals make sense of their world and their experiences as they are lived. Hermeneutic research is interpretive and uses the meanings of the experiences of the participants.²³ It emphasizes the acquisition and interpretation of an experience as essential to understanding phenomena,^{24,25} such as that of being in the world as a woman living with cardiac pain and a physical disability. Women with mobility limitations were recruited through snowball non-probability convenience sampling, using social media platforms (eg, Twitter, Facebook groups aligned with the target population) and partnerships with the Network of Women with Disabilities (NOW), the Canadian Council of Disabilities (CCD), and the DisAbleD Women's Network (DAWN). Consistent with the International Classification of Functioning, Disability and Health,²⁶ women with CAD over the age of 40 years were eligible if they responded "yes, sometimes" or "yes, often" to any of the following 3 questions (Q): "Does a long-term physical condition or mental condition or health problem, reduce the amount or the kind of activity you can do": (Q1) "at home?"; (Q2) "at work?"; and (Q3) "in other activities (eg, transportation, leisure)?" Heart disease was self-reported by women who had a history of: (i) cardiac pain and/or cardiac symptoms that may have included excessive breathlessness/dyspnea and extreme fatigue/tiredness ≥ 3 months, and (ii) having a coronary angiogram, percutaneous coronary intervention, and/or coronary artery bypass graft surgery. Women were excluded if they were not able to speak or read English, had severe cognitive impairment (assessed with the Six-Item Screener²⁷), or major comorbid medical or psychiatric illness that could have precluded their ability to participate in an interview. Ethics approval was granted by the University of Toronto Health Sciences Ethics Board, Canada (Reference 37113).

Data collection and analysis

Nine of the targeted 10 women were recruited to participate in individual semistructured interviews between October 9, 2019 and April 15, 2021. One participant consented but was not able to commit to an interview due to personal responsibilities. Eight interviews were completed, all interviews were recorded, and the mode of delivery (ie, telephone, remote, face-to-face) was chosen based on participant convenience. A total of 3 to 10 interviews were recommended by Creswell²⁸ for phenomenological studies, and by Kuzel²⁹ for homogeneous samples. Data richness was evaluated after each successive interview, with a focus on credibility and coherence and an original and meaningful contribution to the existing evidence.³⁰ Each interviewee filled out an investigator-developed demographic form, and comorbidities were assessed using an adapted version of the Functional Comorbidity Index.³¹

One-hour semistructured interviews were conducted by the principal investigator, and field notes were made by another member of the investigative team. The interview was informed by Boyd's model for healthcare co-design³² and previous studies that reported details of interviews with women who have heart disease.^{33,34} Specifically, pre-, peri-, and post-diagnostic cardiac pain experiences were explored, using gendered elements of disability spanning micro, meso, and macro levels. In order to explore as close to the lived experience as possible, questions were open-ended, and

follow-up discussion was primarily led by the participant. New insights were developed through an exchange of dialogue, designed to determine what participants really experienced, from the inside out, and not simulations of what they thought they had experienced. The principal investigator and participant attempted to bring life to the experiences being explored, through the use of open dialogue, a hermeneutic circle, and attention to language.²³ Data were analyzed using a hermeneutic phenomenological approach inspired by Ricoeur, following that of Lindseth and Norberg.³⁵ We began with self-reflection as a preparatory step to the analysis. We did not set aside or bracket our biases or assumptions as one would do in phenomenology; rather, we embedded these into the interpretation of the data.²³ In this approach, a "naïve reading" was first conducted wherein the text was interpreted using phenomenological language. This interpretation of the text was then used to guide a thematic structural analysis, as outlined by Lindseth and Norberg,³⁵ which consisted of dividing data into "meaning units" and using quotes from the transcripts that conveyed a singular meaning. Quotes were then "condensed" (ie, meanings were explained in concise and simple language). To maintain authenticity and accurately convey the experiences reported in the interviews, focus was placed on interpreting meaning units through the experiences of the interviewees. We tried to understand the context in which each participant's dialogue was produced so we could accurately interpret the meaning of the text. Similar meaning units were then grouped into subthemes and themes based on similarities between their condensed forms. The investigators referred back to the data regularly to ensure accuracy, following the hermeneutic approach to interpretation.³⁶ In the last step of the analytical process, the text was reviewed once again in a holistic manner, taking into consideration our prior understanding of cardiac pain experiences in women. Thus, interpretations were generated from the text and its context, the participants, us as researchers, and our contexts.²³ As researchers, we were reflective, sensitive to the language of participants and open to their lived experiences.

Results

The mean age of participants was 59 ± 8 years; 3 (37%) self-reported as belonging to a racial and ethnic minority group; and 1 woman (13%) identified as Indigenous. The remaining women ($n = 5$; 63%) were White, as categorized in the updated guidance on the reporting of race and ethnicity.³⁷ Half the women ($n = 4$) had graduate degrees, and most were either unemployed or retired ($n = 7$; 88%). Demographic characteristics are provided in Table 1.

All the women had a long-term physical or mental condition or health problem that reduced the amount or kind of activity they did at home, work, and/or in other arenas. They also had a variety of comorbid conditions that most often included visual impairment ($n = 6$; 75%), neurologic disease (eg, multiple sclerosis; $n = 5$; 63%), and arthritis ($n = 5$; 63%). Three women (37%) had a myocardial infarction, and 2 (25%) had peripheral vascular disease. One woman (13%) reported heart failure. Most of the women ($n = 5$; 63%) had lived with cardiac pain and/or symptoms for more than 5 years—5 (63%) had undergone a coronary angiogram, 3 (37%) had undergone percutaneous coronary intervention (ie,

Table 1. Demographic characteristics of participants (N = 8)

Characteristic	n (%)
Comorbidities	
Visual impairment	6 (75)
Neurologic disease	5 (63)
Arthritis	5 (63)
Depression	4 (50)
Hearing loss	4 (50)
Diabetes	4 (50)
Stroke	3 (37)
Osteoporosis	3 (37)
Myocardial infarction	3 (37)
Peripheral vascular disease	2 (25)
Anxiety	2 (25)
Upper gastrointestinal disease	2 (25)
Heart failure	1 (13)
Asthma	1 (13)
Chronic obstructive pulmonary disease	0 (0)
Education	
Elementary	2 (25)
Secondary	2 (25)
Diploma/certificate	0 (0)
Bachelor's degree	0 (0)
Master's degree	4 (50)
PhD	0 (0)
Employment	
Full-time	0 (0)
Part-time	1 (13)
Unemployed	3 (37)
Retired	4 (50)

stent), and only 1 (13%) had undergone coronary artery bypass graft surgery. Cardiac pain experiences were described as tightness (n = 3; 38%) in the chest (n = 5; 63%) that radiated to the left shoulder (n = 2; 25%), neck (n = 2; 25%), and arm(s) (n = 2; 25%). Half of the women (n = 4) were unaware of the cardiac pain triggers, which most often were reported during the evening or night (n = 4; 50%). Prodromal symptoms included fatigue or extreme exhaustion (n = 3; 38%), difficulty sleeping (n = 2; 25%), dizziness (n = 2; 25%) and shortness of breath (n = 2; 25%).

Structural analysis of transcripts

Similar to Guest,³⁸ we had rich data material that deepened our understanding of cardiac pain experiences in women with disabilities, after 8 interviews. All interviews were conducted either by telephone or otherwise remotely and lasted between 40 and 65 minutes (mean: 52 minutes; standard deviation: 10.140). Participant #5 had a disability that impacted her speech, so her caregiver acted as an interpreter during the interview. Through a structural analytic approach, 2 main themes were uncovered: (i) the diagnostic journey, and (ii) life with cardiac symptoms and a disability. Under the first main theme, subthemes included making a decision, resource barriers, attitudinal barriers, neglect, and power imbalance. Under the second theme, the subthemes were quality of life, supports, patient-provider relationship, self-management, and advocacy. The analytic process, including the main themes and subthemes, are outlined in [Supplemental Table S1](#).

Themes

Diagnostic journey. This theme included subthemes that described barriers and challenges women with disabilities

faced during the process of receiving a diagnosis for their cardiac pain or symptoms.

Making a decision. Depending on the symptom severity or type, the length of time before the women decided to seek care from a healthcare provider varied. Most described that they could “sense” or “judge” when they needed to go to the hospital for new, unresolved, or worsening symptoms. However, participants also “tried to think of things it might be” (patient [P]2), and this resulted in attributing cardiac symptoms to less life-threatening conditions. For example, a participant (P2) had pain radiating to her collar bone, and described it as follows: “in school gym one time I broke my collar bone and oh maybe I’m getting old or it’s arthritis.”

Resource barriers. Six of the women described that transportation was a barrier to accessing care during the diagnostic process. The majority of them relied on public transit or intercity buses and trains to get to appointments. In urban areas, busing for disabled persons was not sufficient and resulted in women deciding a trip “is not worth it” (P4) because of the additional transit time and requirements to book early in advance. Often, women living in both urban and rural areas traveled to different cities or provinces for healthcare, particularly for specialist care. Seeking such care appeared to be an issue if they did not feel they could trust their local providers to give them adequate care and felt it necessary to travel out of town. Intercity travel presented more time and cost barriers to accessing care. Following surgical procedures, patients were required to make arrangements to be picked up, so without social support such as a friend to drive them, the women had to pay for a taxicab. On the day of the operation, P1 “ended up taking a cab but that was like \$65.00 which is a phenomenal amount of money.” Participants further emphasized the challenges they faced relating to wait times to see specialists, which they felt increased their health risks significantly. This delay in access to care was especially concerning for those participants that did not know how to differentiate potential cardiac symptoms from symptoms they typically experienced due to other conditions or disabilities. Cardiac rehabilitation programs and physical activity sessions were not attended, due to accessibility issues, which participants felt delayed treatment options and worsened their cardiac health. Accessible healthcare sites and materials were not common in women’s experiences, resulting in late appointments and improper examinations: “If it wasn’t for me doing a pivot transfer for certain tests that she does do, she doesn’t know how she would get her tests done. They’ve never tried to modify anything for her, and even for me, I have to physically transfer her myself” (caregiver for P5).

Attitudinal barriers. The women mentioned instances in which they were disturbed by comments made by healthcare providers. For example, one participant (P2) said:

“[The nurse] was down the corridor and she was talking to this other person who was working there. And she’s like we’ve got two albinos out in the waiting room but you know they seem really nice. They seem like normal people. And I thought to myself what a terrible thing to say.” Others reported that they felt it was difficult to receive a proper

diagnosis because their symptoms were attributed to their disability, and they were sent away without sufficient investigation of their cardiac symptoms. Descriptions of their experiences appeared to indicate that excessive focus was put on their disability at the expense of other aspects of their personhood. One participant said: “I walk with a walker and they see me with a walker, and they know I have neurological symptoms, they just automatically think that your dizziness is neurological. It can't be any heart thing” (P3). Excessively long wait times in the emergency room, and the lack of individualized care, as well as a lack of communication between provider and participant, made these women feel as though their concerns were invisible.

Neglect. Women felt they did not have the power to be involved in their care decisions. Some felt intimidated by the healthcare provider's qualifications, and therefore did not advocate for themselves or even question their provider. This reticence appeared to be due to their feelings of inferiority caused by their lack of formal education in the medical field. Those who felt that they were not being given adequate information took it upon themselves to learn on their own; this created a greater feeling of mistrust toward their healthcare provider(s). Some were not even told about health events that they had been through (eg, myocardial infarction), were left unattended for long periods of time in emergency departments, and generally felt devalued as people (P2):

It was sort of like we're just doing these things, you're the patient but you don't need to say anything or ask anything because I would get very... I must admit I get very intimidated when I go to doctors. I don't a lot of times ask questions because I'm afraid to because I'm not sure how I phrase this. ... I didn't even finish high school. I have got lessons in life but I don't have the education and so, I do get very intimidated by educated people.

I felt very neglected and even with the testing and stuff, the people acted like well you know you're a specimen. They didn't act as if I was a real person.

Life with cardiac symptoms and a disability

Quality of life. Many participants were distressed about their treatment and plan of care. They did not feel they were given answers, and this provoked anxiety and misunderstandings about the severity of their cardiac condition. They did not feel comfortable within the healthcare system and felt invalidated regarding their health concerns and in their ability to advocate for themselves. This feeling caused distress and deterred them from seeking further care. Participants felt as though they had to put in more effort to prove their value as a person and a patient with a disability, as exemplified by P3:

And so, you can't say to a doctor, well, maybe, you want to refer me to a better specialist because you are no good? You can't say that to doctors. You have to find another specialist. You have to get your family doctor to send you to see a better one. It's always a fight. You get tired of fighting. Not only do you feel vulnerable, but you get tired. After a while, you just say, well, you know what, if I die from a heart attack at home, well, that's it, really. Do I want to go to the emergency room? No. It gets to that point sometimes, where you just don't even want to see doctors anymore. If you have been badly treated a few

times, that can happen, where you just don't want to go anymore. If it happens to me, I can imagine it can happen to a lot of people.

The complexity of multiple conditions made diagnosis and treatment difficult. Those women who felt their cardiac symptoms were mistakenly related to their disability experienced a worsening of symptoms due to unnecessary or excessive medication they were prescribed. Participants who believed their provider correctly diagnosed their condition were able to move to appropriate treatment (P2):

I stayed overnight but I was like instantly I felt better. . . . So it took me a while for my. . . stomach to heal from the ulcerations because of the heartburn. . . , the acid burn I had for so long. But like physically as soon as I had that stent immediately I felt tired. You feel like you've been beat up because you're nervous but it was like instantaneously I felt 30 years younger and I still haven't. . . I'm good. I don't notice. I still feel really good. I'm 65 now. I still feel good.

Supports. Peer support groups can be a source of information, as participants felt encouraged by others on ways to access proper care. Women who were a part of peer groups spoke of them as a source of strength that brought a sense of community for them. Friends and family were significant supports as well, especially for at-home care and when symptom severity increased: “That's right. I belong to a very strong, very close-knit and big stroke survivor group, and we have over 200 members, caregivers and survivors” (P7). Financial support from family and assistance with transportation relieved burden. Access to caregivers, physiotherapists, housing, teaching materials with larger fonts, and government supports (eg, financial assistance programs) significantly improved the management of cardiac health for these women. Those who did not have this access found that obtaining support for their cardiac health was significantly more challenging. “As for cardiac rehab, I said I'm sorry because it would be too costly having to go back and forth because I don't live here” (P2).

Patient-provider relationship. The sex of the healthcare provider appeared to influence the women's healthcare experience, which subsequently contributed to the provider-patient relationship. Women appeared to have a greater level of comfort and mutual understanding when care was provided by a professional of the same sex. “[Her GP is a woman] and she prefers now dealing with women more” (caregiver for P5). “She (the respirologist) has always been very kind, not judgmental, always taken the time to explain to me” (P1).

Self-management. Many of the participants modified their lifestyle to promote health and stop disease progression. They realized they had to manage both their mental and emotional health as much as their physical health associated with their heart disease. They kept themselves “focused and busy” (P7) to distract themselves from psychological stress, and they incorporated exercise and healthy eating to lessen the strain on their bodies and promote healing. Some saw this as integral to their overall health and well-being. “I do a lot of crafts, and so that's really how I occupy my. . . address my stress level, I guess, is that I try to be creative” (P8). “See, that's what's

helping me, is that I'm taking care of myself. I still take walks, 15, 20 minutes, even if it's hard for me to do it" (P3).

Advocacy. Participants felt a need to self-advocate for better care for not only themselves, but for "others with disabilities who had similar experiences" (P5). "Believe it or not, she makes the doctors do these tests always. . . she'll push for [a pharmacological stress test]. You need to do a little bit of research on it so you know what to talk about when you go there. . . she's definitely her own advocate" (caregiver for P5).

Discussion

These qualitative findings suggest that healthcare system improvements are needed in the care of women with disabilities and heart disease in Canada. The interviews indicated that women who live with a physical disability are not usually partners in decision-making concerning their health. Participants described feeling "pushed to the side," discouraged from voicing their needs or asking questions about their heart disease. These women believed that their feelings threatened the trust they had in the healthcare system and caused them mental anguish. This made them less likely to seek further care, even if their condition or symptoms became more severe. Underdiagnosis and undertreatment of women with cardiac pain or symptoms is a recognized problem,³⁹⁻⁴¹ yet the experiences of women are poorly described.⁴² Women in general describe being "stopped at the gate" in the emergency department, especially when their cardiac pain and symptoms differed from those traditionally ascribed to men.⁴² Women in our qualitative study felt isolated and couldn't get anyone's attention in the emergency department: "I didn't have my wheelchair so I was not mobile, so they put me in a bed in a room. . . the buzzer in the room didn't work." Previous evidence suggests that trust in a healthcare institution and provider is impacted by negative prior experience.⁴³ This finding suggests that access to care for women with cardiac pain, physical disabilities, and heart disease is similar to that for women with cardiac pain, no physical disabilities, and heart disease. However, cardiac pain experiences appeared to be more negatively affected for women who had physical disabilities and mobility limitations.

In our qualitative study, women with physical disabilities indicated they were able to make appropriate choices even when faced with healthcare challenges; they distanced from discordant healthcare providers, educated themselves, and attempted to adopt healthy lifestyle choices. In contrast, women who had positive healthcare experiences were more likely to seek further care. This finding is consistent with the findings of Eton et al.⁴⁴ who reported that patients who had good relationships with healthcare providers were more likely to have better physical and mental health. This impact extended beyond the patient-provider relationship for these women.

Participants indicated that local healthcare systems did not appropriately accommodate their physical needs as people with disabilities. Inaccessible buildings, care sites, educational material, and procedures were common to all of the women. These results are congruent with a recent systematic review that reported that a lack of accessible equipment in healthcare

sites, inaccessible buildings, and transportation costs were barriers to healthcare access for women with disabilities.⁴⁵ These barriers are not simple inconveniences—the basic standard of care that is expected for patients in Canadian healthcare contexts cannot be met for these women when they must have a physical examination performed while they are in their wheelchair because they are unable to get on an examination table in a clinic. Such experiences are consistent with the findings of Stillman et al.⁴⁶ in the US, where wheelchair users were found to be less likely to receive adequate physical examinations and other preventative care.

Cardiac rehabilitation programs often were not accessed by women with physical disabilities, especially when they lived in more remote or rural areas. High costs, unreliable transportation, and gendered roles (eg, doing housework) limited access to these specialty services for many women. These results are consistent with those of other studies that report a general underutilization of cardiac rehabilitation programs by women,^{47,48} women who have musculoskeletal disorders,⁴⁹ and women who live a fair distance from cardiac rehabilitation facilities.⁴⁸ Women with physical disabilities who have higher risk for heart-related hospitalization need access to accessible and gender-tailored cardiac rehabilitation.⁵⁰ Despite the benefits of exercise-based cardiac rehabilitation,⁵¹ these services are generally underutilized by women.⁵² A recent Cochrane review suggested that remote and home-based programs were effective in improving cardiac rehabilitation adherence (standardized mean difference: 0.56; 95% CI: 0.37, 0.76).⁵³ However, very little evidence to date describes cardiac rehabilitation specifically for women with physical disabilities. The concept of co-design as a quality-improvement methodology described by Boyd et al.³² suggests that women with disabilities should be invited to collaborate in the development of their healthcare services, such as remote and home-based cardiac rehabilitation programs.

Strengths of this study include interviews that were conducted with women who live with a physical disability and heart disease. Women with heart disease are generally under-researched, underdiagnosed, undertreated, undersupported, and under-aware,⁵⁴ especially women with heart disease who also live with a physical disability.⁵⁵ Women with heart disease and a physical disability face these hurdles in the Canadian healthcare system, which should be of concern to practitioners, educators, and administrators. These women had fewer resources and protective factors¹⁹ and were trying to manage their heart disease while navigating with their disability; they lived with the consequences of sex- and gendered-actions or inactions manifested by the Canadian healthcare system.

Emphasizing the concepts of credibility, reflexivity, transparency, and transferability—as outlined by Williams, Boylan, and Nunan⁵⁶—was important for the researchers of this study. The credibility of our results comes from the fact that the interpretations were derived from firsthand accounts of women living with cardiac pain and a physical disability. Methods were carefully detailed, including making audio recordings of all interviews, which were then transcribed and checked against the original audio recording to validate transcription accuracy.⁵⁷ Transcripts were analyzed by multiple members of the research team, creating an analytical space with room for nuances, with frequent discussion among the

team members concerning the interpretations derived, throughout the analysis. Personal experiences, expertise, and biases regarding cardiac pain experiences in women with physical disabilities were reflected on, shared, and attended to during data collection and analysis, adhering to the traditions of reflexivity and hermeneutic phenomenology.^{35,58,59} The researchers were fully transparent in all aspects of the research process, as all data collection and analytical processes were outlined in the methods. And although our methods enabled us to access a sample that is potentially difficult to reach, we were unable to make generalizations or suggest that our findings are transferable to other women living with cardiac pain and a physical disability.^{57,60}

Knowledge, beliefs, and practices regarding women's heart health are lacking among Canadian physicians,⁶¹ a situation similar to that in the US, where 22% of primary care physicians and 42% of cardiologists felt prepared to assess cardiovascular disease risk in women, and only 39% of primary care physicians made cardiovascular disease a priority.⁶² The authors acknowledge the potential study limitation that the opinions and views of healthcare providers were not investigated to provide additional insight into their awareness, diagnosis, and treatment of heart disease for women with physical disabilities. Future studies could focus on both patient and provider perspectives, for a more informed view of women with heart disease and disability within the Canadian healthcare system. In addition, we recognize that the sample size in this study is small; however, we retrieved rich sources of data from this sample,³⁰ detailing various types of experiences of women with disabilities from across Canada. These rich sources of data were enough to support our subthemes and themes, congruent with the findings of Guest et al.,³⁸ who reported that generally data are sufficient to support all meta-themes uncovered in a thematic analysis, by the sixth interview. Snowball sampling also has benefits and limitations. Although our methods enabled us to access a sample that is potentially difficult to reach, we are unable to make the generalization that our findings are representative of all women living with cardiac pain and a physical disability.⁶⁰ Moreover, snowball sampling using social media platforms may introduce sampling bias toward women who have an online presence, and thus may not be representative of women living with cardiac pain and a physical disability who do not utilize Twitter or Facebook.⁶³

This study is a clear indication that discussion around greater equity and inclusion in Canadian healthcare must include women with disabilities. Students in the healthcare professions need to receive better education in the care of people with disabilities. In Stillman et al.'s study,⁴⁶ more than half of participants mentioned that they did not believe that their healthcare provider had more than a "moderate understanding" of their unique medical needs related to their disability. Strategies to increase awareness, diagnosis, and treatment in women with cardiac pain and disability are needed. More research is needed on a national level to understand Canadian issues, and on provincial and municipal levels to address deficiencies and needs specific to each locality. This need is supported by the findings of Selick et al.⁶⁴ in their qualitative study on the experiences of people with intellectual and developmental disabilities in Ontario, which suggested that strategies such as establishing national

guidelines and determining needs based on local data are important for engagement of healthcare providers in Ontario's emergency and primary care settings.

Conclusion

These interviews provide early insights into needed changes on the micro, meso, and macro levels for women with cardiac pain and physical disabilities in Canada. The needs of these women need to be made visible, and they need to know that their health—physical, mental, emotional, and spiritual—is valued just as much as that of women without disabilities. The information in this paper could be used to enhance clinical care and education of healthcare professionals in training, create cardiac rehabilitation programs, and increase research capacity regarding the care of people with disabilities in the healthcare system.

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References

- Morris S, Fawcett G, Brisebois L, Hughes J. A demographic, employment and income profile of Canadians with disabilities aged 15 years and over. Available at: <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm>. Accessed May 8, 2021.
- Editorial. World report on disability. *Lancet* 2011;377:1977.
- Burlock A. Women in Canada: a gender-based statistical report—women with disabilities. Statistics Canada, 2017.
- Norris C, Yip C, Nerenberg K, et al. Introducing the Canadian Women's Heart Health Alliance ATLAS on epidemiology, diagnosis, and management of cardiovascular disease in women. *CJC Open* 2020;2:145-50.
- Norris C, Yip C, Nerenberg K, et al. State of the science in women's cardiovascular disease: a Canadian perspective on the influence of sex and gender. *J Am Heart Assoc* 2020;9:e015634.
- Man J, Beckman J, Jaffe I. Sex as a biological variable in atherosclerosis. *Circ Res* 2020;126:1297-319.
- Pelletier R, Khan N, Cox J, et al. Sex versus gender-related characteristics. *J Am Coll Cardiol* 2016;67:127-35.
- Pelletier R, Humphries K, Shimony A, et al. Sex-related differences in access to care among patients with premature acute coronary syndrome. *CMAJ* 2014;186:497-504.
- Canadian Institutes of Health Research. On-line training modules: integrating sex & gender in health research. Available at: <http://www.cihr-irsc.gc.ca/e/49347.html>. Accessed April 23, 2019.

10. Canto J, Canto E, Goldberg R. Time to standardize and broaden the criteria of acute coronary symptoms presentations in women. *Can J Cardiol* 2014;30:721-8.
11. Kirchberger I, Heier M, Wende R, von Scheidt W, Meisinger C. The patient's interpretation of myocardial infarction symptoms and its role in the decision process to seek treatment: the MONICA/KORA Myocardial Infarction Registry. *Clin Res Cardiol* 2012;101:909-16.
12. Pepine C, Ferdinand K, Shaw L, et al. Emergence of nonobstructive coronary artery disease: a woman's problem and need for change in definition on angiography. *J Am Coll Cardiol* 2015;66:1918-33.
13. Sjostrom-Strand A, Fridlund B. Women's descriptions of symptoms and delay reasons in seeking medical care at the time of a first myocardial infarction: a qualitative study. *Int J Nurs Stud* 2008;45:1003-10.
14. von Eisenhart Rothe A, Albarqouni L, Gartner C, et al. Sex-specific impact of prodromal chest pain on pre-hospital delay time during an acute myocardial infarction: findings from the multicenter MEDEA Study with 619 STEMI patients. *Int J Cardiol* 2015;201:581-6.
15. Krahn G, Walker D, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health* 2015;105: S198-206.
16. Johnsen N, Davidsen M, Michelsen S, Juel K. Health profile for Danish adults with activity limitation: a cross-sectional study. *BMC Public Health* 2017;18:46.
17. Iezzoni L, Yu J, Wint A, Smeltzer S, Ecker J. General health, health conditions, and current pregnancy among US women with and without chronic physical disabilities. *Disabil Health J* 2014;7:181-8.
18. Alper J. *People Living with Disabilities: Health Equity, Health Disparities, and Health Literacy: Proceedings of a Workshop*. Washington, DC: National Academies Press, 2018.
19. Savage A, McConnell D. The marital status of disabled women in Canada: a population-based analysis. *Scand J Disabil Res* 2016;18: 295-303.
20. Castro O, Ng K, Novoradovskaya E, Bosselut G, Hassandra M. A scoping review on interventions to promote physical activity among adults with disabilities. *Disabil Health J* 2017;11:174-83.
21. Ahn S, Basu R, Smith M, et al. The impact of chronic disease self-management programs: healthcare savings through a community-based intervention. *BMC Public Health* 2013;13:1141.
22. Gulley S, Rasch E, Bethell C, et al. At the intersection of chronic disease, disability and health services research: a scoping literature review. *Disabil Health J* 2018;11:192-203.
23. Laverly S. Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *Int J Qual Meth* 2003;2:21-35.
24. Heidegger M. *Being and Time*. Oxford, UK: Blackwell Publishers Ltd, 1962.
25. Morgan DA. Analysing complexity: developing a modified phenomenological hermeneutical method for data analysis for multiple contexts. *Int J Soc Res Method* 2021;24:655-67.
26. World Health Organization (WHO). *How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO, 2013.
27. Callahan C, Unverzagt F, Hui S, Perkins A, Hendrie H. Six-item screener to identify cognitive impairment among potential subjects for clinical research. *Med Care* 2002;40:771-81.
28. Creswell J. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage, 1998.
29. Kuzel A. Sampling in qualitative inquiry. In: Crabtree B, Miller W, eds. *Doing Qualitative Research*. Newbury Park, CA: Sage, 1992:31-44.
30. Thorne S. The great saturation debate: what the "S Word" means and doesn't mean in qualitative research reporting. *Can J Nurs Reseach* 2020;52:3-5.
31. Groll D, To T, Bombardier C, Wright J. The development of a comorbidity index with physical function as the outcome. *J Clin Epidemiol* 2005;58:595-602.
32. Boyd H, McKernon S, Mullin B, Old A. Improving healthcare through the use of co-design. *N Zea Med J* 2012;125:76-87.
33. Bjornnes A, Parry M, Leegaard M, et al. Self-management of cardiac pain in women: a meta-summary of the qualitative literature. *Qual Health Res* 2018;1-19.
34. Parry M, Bjornnes A, Victor J, et al. Self-management interventions for women with cardiac pain: a systematic review and meta-analysis. *Can J Cardiol* 2018;34:458-67.
35. Lindseth A, Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2004;18:145-53.
36. Koch T. An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Res* 1999;6:20-34.
37. Flanagan A, Frey T, Christiansen S. Updated guidance on the reporting of race and ethnicity in medical and science journals. *JAMA* 2021;326: 621-7.
38. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Meth* 2006;18: 59-82.
39. Meyer M, Bernheim A, Kurz D, et al. Gender differences in patient and system delay for primary percutaneous coronary intervention: current trends in a Swiss ST-segment elevation myocardial infarction population. *Eur Heart J Acute Cardiovasc Care* 2019;8:283-90.
40. Maas A, van der Schouw Y, Regitz-Zagrosek V, et al. Red alert for women's heart: the urgent need for more research and knowledge on cardiovascular disease in women. *Eur Heart J* 2011;32:1362-8.
41. Westerman S, Wenger N, Wenger N. Women and heart disease, the underrecognized burden: sex differences, biases, and unmet clinical and research challenges. *Clin Sci* 2016;130:551-63.
42. Colella T, Hardy M, Hart D, et al. The Canadian Women's Heart Health Alliance atlas on the epidemiology, diagnosis, and management of cardiovascular disease in women—Chapter 3: patient perspectives. *CJC Open* 2021;3:229-35.
43. Schwei R, Kadunc K, Nguyen A, Jacobs E. Impact of sociodemographic factors and previous interactions with the health care system on institutional trust in three racial/ethnic groups. *Patient Educ Couns* 2014;96: 333-8.
44. Eton D, Ridgeway J, Linzer M, et al. Healthcare provider relational quality is associated with better self-management and less treatment burden in people with multiple chronic conditions. *Patient Pref Adher* 2017;11:1635-46.
45. Matin B, Williamson H, Karyani A, et al. Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. *BMC Women's Health* 2021;21:44.
46. Stillman M, Bertocci G, Smalley C, Williams S, Frost K. Healthcare utilization and associated barriers experienced by wheelchair users: a pilot study. *Disabil Health J* 2017;10:502-8.

47. Grace S, Turk-Adawi K, de Araujo Pio C, Alter D. Ensuring cardiac rehabilitation access for the majority of those in need: a call to action for Canada. *Can J Cardiol* 2016;32:S358-64.
48. Ruano-Ravina A, Pena-Gil C, Abu-Assi E, et al. Participation and adherence to cardiac rehabilitation programs. A systematic review. *Int J Cardiol* 2016;223:436-43.
49. Marzolini S, Oh P, Alter D, Stewart D, Grace S. Musculoskeletal comorbidities in cardiac patients: prevalence, predictors, and health services utilization. *Arch Phys Med Rehabil* 2012;93:856-62.
50. Turk-Adawi K, Supervia M, Lopex-Jimenez F, et al. Women-only cardiac rehabilitation delivery around the world. *Heart Lung Circ* 2021;30:135-43.
51. Lavie C, Milani R. Effects of cardiac rehabilitation and exercise training on exercise capacity, coronary risk factors, behavioral characteristics, and quality of life in women. *Am J Cardiol* 1995;75:340-3.
52. Way K, Reed J. Meeting the needs of women in cardiac rehabilitation. *Circulation* 2019;139:1247-8.
53. Santiago de Araújo Pio C, Chaves G, Davies P, Taylor R, Grace S. Interventions to promote patient utilisation of cardiac rehabilitation. *Cochrane Database Syst Rev* 2019;2:CD007131.
54. Heart & Stroke Foundation. Ms.Understood. Available at: https://www.heartandstroke.ca/-/media/pdf-files/canada/2018-heart-month/hs_2018-heart-report_en.ashx. Accessed February 20, 2021.
55. Jaffer S, Foulds H, Grewal J, et al. The Canadian Women's Heart Health Alliance ATLAS on the epidemiology, diagnosis, and management of cardiovascular disease in women. Chapter 2: the scope of the problem. *CJC Open* 2020;3:1-11.
56. Williams V, Boylan A, Nunan D. Critical appraisal of qualitative research: necessity, partialities and the issue of bias. *BMJ Evid Based Med* 2020;25:9-11.
57. Ramsook L. A methodological approach to hermeneutic phenomenology. *Int J Hum Soc Sci* 2018;10:12-24.
58. Steinskog T, Tranvag O, Nortvedt M, Ciliska D, Graverholt B. Optimizing a knowledge translation intervention: a qualitative formative study to capture knowledge translation needs in nursing homes. *BMC Nurs* 2021;20:106.
59. Spence D. Supervising for robust hermeneutic phenomenology: reflexive engagement within horizons of understanding. *Qual Health Res* 2017;27:836-42.
60. Sharma G. Pros and cons of different sampling techniques. *Int J Appl Res* 2017;3:749-52.
61. McDonnell L, Turik M, Coutinho T, et al. Women's heart health: knowledge, beliefs, and practices of Canadian physicians. *J Women's Health* 2018;27:72-82.
62. Bairey Merz C, Andersen H, Sprague E, et al. Knowledge, attitudes, and beliefs regarding cardiovascular disease in women. *J Am Coll Cardiol* 2017;70:123-32.
63. Leighton K, Kardong-Edgren S, Schneidereith T, Foisy-Doll C. Using social media and snowball sampling as an alternative recruitment strategy for research. *Clin Simul Nurs* 2021;55:37-42.
64. Selick A, Durbin J, Casson I, Lee J, Lunskey Y. Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: What do staff tell us? *Health Promo Chron Dis Prev Can* 2018;38:349-57.

Supplementary Material

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