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# Canadian Journal of Cardiovascular Nursing

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# Canadian Journal of Cardiovascular Nursing

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# Editorial: Cardiovascular Nursing Is a Profession—And History Makes That Clear

In an evolving era filled with political and social unrest, nurses more than ever have a critical role to play in advancing the health and wellbeing of all people across Canada and beyond. Recent public statements emerging from the United States have set forth debate regarding the professional nature of nursing education, revealing a deeply outdated and harmful understanding of both modern nursing and its critical contributions. CJC/N Editors Davina and Krystina recently attended an engagement event at the Canadian parliament in Ottawa, hosted by the Canadian Nurses Association. Here, we met with politicians and a diverse range of nursing organizations to highlight the evolving role of nursing today and advocating for advancing contributions to support a better tomorrow.

## A Profession Rooted in Science, Expertise, and History

Nursing in Canada did not emerge spontaneously; it evolved through more than a century of increasingly formalized education, rigorous professionalization, and scientific advancement. In the early 20th century, nursing education transitioned away from hospital apprenticeship models into academic settings. By the 1960s and 1970s, Canadian provinces began formally shifting toward college- and university-based programs, guided by a recognition that nurses required theoretical knowledge, critical thinking, and research literacy. The turning point came in the late 20th and early 21st centuries, when provinces such as British Columbia, Alberta, Manitoba, Ontario, and others made the baccalaureate degree the minimum entry-to-practice requirement. Alongside this, graduate degrees and specialized certificates have continued to evolve, positioning nurses to respond to the increasingly complex needs of the people of Canada.

## Cardiovascular Nursing in Canada

At a time when cardiovascular disease remains the leading cause of death nationwide, there has never been a greater need for nursing professionals across all spheres of health-care. For the **Canadian Council of Cardiovascular Nurses**,

this is reflected in our mission to advance excellence in cardiovascular care through education, leadership, and research. Cardiovascular nurses exemplify the highest level of professional nursing practice, requiring a rich and diverse knowledgebase. Through this, cardiovascular nurses provide care across many acute and community healthcare settings and through a wide range of roles, including clinic and hospital nurses, nursing educators, advanced practice nurses, healthcare leaders, researchers, and more.

## Cardiovascular Nursing Leads the Way

Professions are defined not only by applying evidence, but also by generating knowledge and advancing its application. In this journal alone, we showcase patient and caregivers' insights and lived experience, synthesized evidence on emerging topics relevant to CV nursing, new programs, opportunities for health system improvement, and advancement of health equity. These activities are all hallmarks of a responsive and skilled profession. Furthermore, cardiovascular care is inherently interdisciplinary, involving cardiologists, surgeons, pharmacists, rehabilitation professionals, physiotherapists, and more. Nurses have a central role in care, both through the application of their clinical expertise, but also through their ability to support the integration of care to best meet patient needs. Cardiovascular nurses provide evidence of this time and time again, offering specialized knowledge and skills.

While critique may lie far from home, nurses across the world must continue to leverage support for those whose professional identity and value lies under threat. Advocating for the importance and role of nurses in addressing healthcare challenges remains of central importance, along with protecting, promoting, and growing our professional identity. Here at CJC/N, we unequivocally support the nursing professions across the globe and are excited to continue to showcase this work through the journal and related Canadian Council of Cardiovascular Nurses activities.

**Drs. Davina Banner and Krystina B. Lewis**

# Postoperative Coronary Artery Bypass Graft Readmissions in Rural, Remote, and Northern Communities: A Case-Control Study Focused on the Social Determinants of Health

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## Abstract

**Background:** People living in rural, remote, and northern communities (RRNCs) are at higher risk for hospital readmissions following coronary artery bypass graft (CABG). The aim of this study was to identify factors associated with hospital readmission post-CABG in Canadian RRNCs, including social determinants of health (SDOH).

**Methods:** In this case-control study, we reviewed 44 patient charts readmitted within 30 days post-CABG to one RRNC hospital and the charts of 44 patients not readmitted to this hospital.

**Results:** Logistic regression analysis revealed that readmission was associated with history of myocardial infarction (OR 2.52; 95% CI 1.49–4.24), fewer days waiting for surgery (OR 1.02; 95% CI 1.00–1.03), living in a larger population centre

(OR 0.18; 95% CI 0.07–0.51), shorter distance (km) to the hospital where the surgery took place (OR 1.01; 95% CI 1.01–1.02), and need for community care post-CABG (OR 14.97; 95% CI 4.03–55.65).

**Conclusion:** Readmission post-CABG was correlated with access to acute and community healthcare.

**Nursing Implications:** There is a need to integrate the SDOH in pre- and post-surgical education, discharge planning, and specialized community services in RRNCs.

**Keywords:** case-control study, rural remote and northern communities, social determinants of health, coronary artery bypass graft, post-operative readmissions

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## Key Highlights

1. Factors for readmission post-CABG were less associated with health-related factors and rather related to access to health services, physical environment, and community factors.
2. Seven of the 12 SDOH are neither routinely collected nor documented in patient charts.
3. There is a need to strengthen CABG clinical pathways by integrating the SDOH in pre- and post-surgical education, discharge planning, and specialized community services in RRNCs.

People living in rural, remote, and northern communities (RRNCs) in Canada have poorer health status and outcomes and experience different healthcare access, as compared to people living in urban areas (Hale et al., 2021; Health

Quality Ontario, 2017; Smale & Holliday, 2020). In RRNCs, cardiovascular disease (CVD) affects more people than any other condition, with approximately **29.8%** of the population affected and many requiring coronary artery bypass graft (CABG) to treat advanced coronary artery disease (CAD; Statistics Canada, 2024; Smale & Holliday, 2020). Recovery from CABG can be challenging, often requiring numerous physical and social supports, with an inherent risk of readmission to hospital for various post-surgical complications, such as respiratory issues and infection (Shawon et al., 2021). Recent data from a pan-Canadian study of cardiac centres reported an average post-CABG readmission rate in one Northern Ontario hospital of 10.6%, while the readmission rate averaged 7.9% across all Southern Ontario hospitals (Canadian Institute of Health Information [CIHI], 2022). These differences



in readmission rates suggest that reasons for readmission go beyond sociodemographic and procedural outcomes and indicate that the social determinants of health (SDOH) may have a role. The SDOH are non-medical factors, whether social, economic, or environmental, that affect a person's health, quality of life, or progression of a disease in a complex and interconnected manner (Government of Canada, 2020). People residing in RRNCs often have different and more pronounced SDOH challenges compared to those living in urban settings (Canadian Association for Rural and Remote Nursing [CARRN], 2020). Factors, such as geography, transportation availability, and systemic resource allocation, including a lack of cardiac rehabilitation services, and reduced availability of home or telehealth support, can account for differences in readmission rates in urban as compared to rural settings (Teshale et al., 2023).

### Rural, Remote, and Northern Communities

Statistics Canada (2021) defines northern communities as the northern sub-regions of each province. Rural communities are defined as any community outside a population centre (Statistics Canada, 2021). Population centres are classified into three groups: small (1,000 to 29,999 residents), medium (30,000 to 99,999 residents), and large (100,000 residents or more), with the last also referred to as urban areas. Remote communities are geographic areas accessible by air or roads built in the winter over land, frozen rivers and lakes (Statistics Canada, 2021).

There are disparities in CVD occurrence and outcomes as a result of the geographic variations between Canadian RRNCs and urban communities (Hale et al., 2021). People living in Canada's RRNCs have 50% higher rates of CVD associated with higher smoking rates, more precarious and stressful work environments, and limited access to specialized care, all risk factors for heart disease (CIHI, 2022). In terms of healthcare access, in Northern Ontario, only three hospitals perform coronary angiograms, servicing more than 700,000 residents (CIHI, 2022), creating a lengthy wait list for patients with confirmed or suspected CAD. During this wait, the disease has the opportunity to progress critically to the point of requiring invasive intervention, such as CABG (Vervoort et al., 2024). Notably, people living in RRNCs who require CABG are at higher risk for hospital readmission as compared to people living in urban areas (CIHI, 2022).

In Canada, the national average for length of stay post-CABG is 4 to 7 days (CIHI, 2022). However, for patients residing in urban communities it is noted to be shorter with high-volume cardiac surgery programs and longer for those residing in rural areas, due to delayed discharge planning or transportation issues (Vervoort et al., 2024). Rural, remote, and northern communities also often lack availability and accessibility of homecare services and telemonitoring, thus further complicating discharge planning (Vervoort et al., 2024).

Current research related to readmissions post-CABG has centred on demographic, clinical, and procedural factors. Researchers have identified comorbidities that increase risk for readmission, including heart failure (Benuzillo et al., 2018; Shah et al., 2019), atrial fibrillation (Shah et al., 2019), myocardial infarction (Benuzillo et al., 2018; Tam et al., 2018), and complications, such as incisional infections (Shah et al., 2019; Tam et al., 2018). Procedural factors, such as length of post-operative stay (Feng et al., 2018; Shah et al., 2019; Tam et al., 2018) and size of the hospital where surgery took place, also affected risk for readmission (Tam et al., 2018). Some attention has been drawn to insurance status, primarily in the United States (Feng et al., 2018; Khoury et al., 2019; Shawon et al., 2021). To our knowledge, no authors have comprehensively studied the SDOH as factors associated with readmission post-CABG in a Canadian context. This represents an important opportunity to address this gap in knowledge and to strengthen the development and delivery of more responsive healthcare services for people living in RRNCs in Canada.

### Research Aim

The overarching aim of this research was to identify the social, demographic, and clinical factors associated with 30-day hospital readmission post-CABG in RRNCs, with principal attention to the SDOH.

### Methods

#### Design

We conducted a retrospective case-control study. We received ethical approval from the Health Sciences North Research Ethics Board (File: 23-002), with administrative approval from the University of Ottawa Research Ethics Board, as this project was conducted in the context of a Masters' thesis project (File: H-03-23-9038). This study used secondary, de-identified administrative health data without direct engagement with Indigenous communities; therefore, an Indigenous-specific ethics review board was not consulted. We collected Indigenous status respecting Ownership, Control, Access, and Possession (OCAP®) principles, which affirm First Nations', Métis', and Inuit's rights to govern their data. While formal community approval was not required, our team acknowledges the importance of Indigenous data sovereignty and encourages future research to engage meaningfully with Indigenous governance and consultation (First Nations Information Governance Centre, 2014). This study is reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (von Elm et al., 2007).

### Theoretical Framework

Winters and Lee's (2018) Rural Nursing Theory and the Government of Canada's (2020) SDOH framework provided the theoretical underpinning for this study. They were used to understand our findings in the context of providing

nursing care to patients undergoing CABG in a RRNC and guiding the interpretation of our results. The Rural Nursing Theory defines health as a way of life and a holistic state of mind for those living in rural environments (Winters & Lee, 2018). The theory offers an in-depth explanation of the characteristics of rural patients' health outlooks and how nurses can tailor their practice to incorporate them. The theory rests on two main assumptions. First, rural residents have a sense of self-reliance; they rely on one's own efforts to maintain health with minimal help from the formal healthcare system (Winters & Lee, 2018). Second, rural residents demonstrate great resilience as they remain strong during tough circumstances (Winters & Lee, 2018).

The Government of Canada (2020) recognizes 12 SDOH: 1) income and social status, 2) employment and working conditions, 3) education and literacy, 4) childhood experiences, 5) physical environments, 6) social supports and coping skills, 7) healthy behaviours, 8) access to health services, 9) biology and genetic endowment, 10) gender, 11) culture, and 12) race / racism. The SDOH play a critical role in achieving and maintaining cardiovascular health, particularly for people living in RRNCs where barriers, such as limited services, transportation challenges, and lower socioeconomic status, are more common. Research has shown that SDOH significantly affect cardiovascular outcomes (Teshale et al., 2023; Vervoort et al., 2024), yet few studies have explored their role in 30-day readmissions post-CABG in rural Canadian populations. This study addresses that gap by examining how social, demographic, and clinical factors, including SDOH, contribute to readmission risk.

## Setting and Population

This study was conducted in Sudbury, Ontario, Canada, at Health Sciences North (HSN), which is the regional tertiary care centre for Northeastern Ontario and an academic teaching facility. Health Sciences North has 25 other sites, including hospitals, outpatient centres, dialysis centres, and more, providing critical, inpatient and outpatient care for more than 500,000 people living in Northern Ontario. Over 500 cardiac surgeries are performed each year at HSN, with a reported 10.6% readmission rate for isolated, open sternotomy CABG surgeries (CIHI, 2022).

Eligible participants included patients: 1) aged 18 years or older who underwent an isolated open sternotomy CABG at HSN between January 1, 2021 and December 31, 2023; and 2) living in a RRNC in Northeastern or Northwestern Ontario, based on a postal code starting with P, including centres with populations greater than 100,000 residents. Patients who met the eligibility criteria were classified as readmitted to HSN within 30 days of CABG (case) or not readmitted (control). Patients in the readmitted group had to be readmitted to HSN for the research team to access their data through the Meditech electronic medical record. We used the *International Classification of Disease*, Eleventh

Edition (ICD-11) codes to identify a coronary artery bypass graft, defined by code PK80.14: other cardiac procedure associated with harm in diagnostic or therapeutic use, open.

## Sample Size and Sampling Methods

The case group included all patients readmitted within 30 days post-CABG between 2021 and 2023. For the control group, a random selection of the same number of non-readmitted patients (1:1), matched by age, sex, and year of CABG (2021, 2022, or 2023) were obtained. The sample size was confirmed once the number of readmitted patients was identified. In retrospective case-control studies, sample size is often determined by the number of available cases, particularly when the outcome is relatively infrequent, as is the case with 30-day readmissions (Sedgwick, 2014). Matching helps study efficiency, even when sample sizes are small to moderate.

## Data collection

Data were extracted from Meditech, the electronic medical record system used at HSN, including information from admission histories, discharge summaries, and consultation notes. Clinical and demographic variables, such as age, sex, comorbidities, medical history, and Indigenous status (as indicated by Non-Insured Health Benefits [NIHB] coverage), were obtained from their admission(s) for their coronary angiogram and/or CABG surgery. Non-Insured Health Benefits coverage, offered under the Indian Act, is used to identify people who self-identify as Indigenous, including First Nations, Inuit, and Métis (Government of Canada, 2019). Procedure-related data included length of stay pre- and post-operatively, time from angiogram to surgery, emergency level of surgery, postoperative complications, and discharge destination. For readmitted patients, additional data were collected on readmission date, reason, length of stay, and any complications. It should be noted that nursing and interdisciplinary care notes, documented on paper and not integrated into Meditech, were not accessible for this study.

Five SDOH were routinely collected and available in inpatient charts, including employment and working conditions; physical environments (i.e., distance from HSN in km, and size of population centre in which the patient resides); social supports; access to health services (need for community care post-discharge); and culture, including but not limited to Indigenous status. Not routinely collected (hence not available) were income, education, childhood experiences, healthy behaviours, biology and genetics, self-identified gender, nor race.

## Analysis

Descriptive and inferential statistical analyses were conducted using the IBM SPSS statistical software (Version 29.0.1.0). Categorical variables were analyzed using

frequencies, an approach used in most retrospective database reviews (Sedgwick, 2014). Continuous variables were analyzed using measures of central tendency including mean, standard deviation, and range. A binary logistic regression analysis was conducted to estimate odds ratios (ORs) with 95% confidence intervals (CIs), assessing the association between 30-day readmission (yes/no) and selected independent variables. Variables included in the regression model were chosen based on clinical relevance, existing literature, and results of preliminary bivariate analyses. The final model included the independent variables as indicated in Table 4. The *p*-values were two-sided, with statistical significance evaluated at an alpha level of .05. Missing data was managed with a pairwise deletion method, ultimately removing missing values from the analysis (Kang, 2013). Given the small number of cases per group, we opted to avoid removing whole cases.

## Findings

Of 1,021 patients who had an isolated CABG at HSN from January 2021 to December 2023, 44 patients (4%) were readmitted to HSN within 30 days of their surgery (cases). Eighteen patients were readmitted in 2021, 10 patients in 2022, and 16 patients in 2023. We reviewed an additional 44 charts of patients who were not readmitted post-CABG (controls), matched (1:1) by age, sex and year, for a total of 88 patient charts.

## Patient and Procedure-Related Characteristics

Hypertension was the most common cardiac comorbidity, followed by hyperlipidemia, and myocardial infarction in the readmitted group (Table 1). Myocardial infarction was associated with a statistically significantly higher odds (OR 2.517; 95% CI 1.493–4.242) of readmission. Ten (25%) patients in the readmitted group had pleural effusion as a postoperative complication (OR 0.750; 95% CI 0.632–0.890) with none in the non-readmitted group.

The non-readmitted group experienced longer wait times for surgery after coronary angiogram, averaging 49.8 days versus 35.1 days (OR 1.016; 95% CI 1.003–1.030). Two patients in the readmitted group, and seven patients in the non-readmitted group did not have angiogram dates noted in their charts, thus their wait time could not be calculated.

The most common readmission diagnosis was heart failure (*n* = 9; 20.5%) and wound infection (*n* = 7; 15.9%; Table 2). Most patients (*n* = 20; 45.5%) did not experience additional complications during their readmission stay; however, seven (15.9%) patients did have a wound infection, which complicated their readmission stay.

## Social Determinants of Health

Most patients (*n* = 30, 68.2%) in the readmitted group resided in a large population centre (urban) and lived an

average 57.8 km away from the hospital. Patients in the non-readmitted group lived an average 182.0 km away. Of the patients who were readmitted, 72.7% (*n* = 32) were discharged home, while the others were discharged to another health care facility (*n* = 6; 13.6%) or a family member's home (*n* = 6; 13.6%). All patients in the non-readmitted group were discharged to their own home. Nearly 60% (*n* = 26; 59.1%) of patients who were readmitted were married and 18.2% (*n* = 8) were single. Yet, 77.3% (*n* = 34) of patients who were not readmitted were married. None were single. In the readmitted group, 6.8% (*n* = 3) identified as Indigenous based on their NIHB insurance status, whereas, there were none in the non-readmitted group.

## Comparisons Between Readmitted and Non-Readmitted Groups

Logistic regression analysis identified several factors significantly associated with 30-day readmission, including a history of myocardial infarction (OR 2.52; 95% CI 1.49–4.24), shorter wait time between coronary angiogram and surgery (OR 1.02; 95% CI 1.00–1.03), living in a larger population centre (OR 0.18; 95% CI 0.07–0.51), residing closer to the surgical hospital (OR 1.01; 95% CI 1.01–1.02), and requiring community care after discharge (OR 14.97; 95% CI 4.03–55.65; Tables 1 and 3). No significant associations were found for the other factors noted.

## Discussion

In this case-control study, we identified patient, procedure, and social-related factors associated with readmission post-CABG in one RRNC hospital in Ontario. To our knowledge, this is the first study to explore the associations between the SDOH and post-CABG readmissions in a Canadian RRNC context. We identified factors through logistic regression that are associated with readmission 30 days post-CABG: 1) previous myocardial infarction, 2) less wait time for surgery post-coronary angiogram, 3) residing in a larger population centre, 4) residing closer to the hospital where surgery took place, and 5) need for community care post-discharge. These findings suggest that readmission is influenced not only by clinical factors but also by access to care, geographic context, and social supports—elements that align with both the SDOH and the Rural Nursing Theory, and emphasize how environment, access, and resources shape health experiences and outcomes in rural populations.

We identified similar patient-related and procedure-related factors as described in the existing literature. These included myocardial infarction (Benuzillo et al., 2018; Tam et al., 2019), wait time for surgery (Feng et al., 2018; Shah et al., 2019; Tam et al., 2018), and a discharge destination other than the patient's home (Feng et al., 2018; Khoury et al., 2019). Tam et al., (2018), in one of the only studies conducted in Canada on this topic, revealed other reasons



**Table 1**

*Participants' Clinical Characteristics, Readmitted vs Non-Readmitted*

	Case Readmitted  N = 44	Control Non-readmitted  N = 44	Odds Ratio	95% Confidence Interval		p value
				Lower	Upper	
Cardiac history, n (%)						
Hypertension	41 (93.2%)	43 (97.7%)	0.318	0.032	3.180	0.141
Hyperlipidemia <sup>§</sup>	39 (88.6%)	44 (100.0%)	0.886	0.797	0.985	0.999
Myocardial infarction	22 (50.0%)	5 (11.4%)	2.517	<b>1.493</b>	<b>4.242</b>	<b>&lt;0.001</b>
Atrial fibrillation	12 (27.3%)	5 (11.4%)	2.925	0.932	9.175	0.017
Heart failure	6 (13.6%)	10 (22.7%)	0.537	0.176	1.634	0.112
Peripheral artery disease	5 (11.4%)	9 (20.5%)	0.499	0.152	1.630	0.464
Non-cardiac history, n (%)						
Diabetes	21 (47.7%)	23 (52.3%)	0.834	0.361	1.924	0.872
Obesity	16 (36.4%)	14 (31.8%)	1.224	0.506	2.961	0.050
Arthritis	14 (31.8%)	6 (13.6%)	2.956	1.014	8.612	0.274
COPD	8 (18.2%)	3 (6.8%)	3.037	0.749	12.320	0.039
Chronic kidney disease	6 (13.6%)	6 (13.6%)	3.316	0.631	17.428	0.021
GERD	6 (13.6%)	5 (11.4%)	1.232	0.347	4.377	0.197
Obstructive sleep apnea	5 (11.4%)	7 (15.9%)	0.678	0.198	2.325	0.148
Recreational drug use*	3 (6.8%)	1 (2.3%)	3.146	0.314	31.484	0.094
CABG-related factor, mean (SD)						
LOS preoperative (days) <sup>¶</sup>	8.0 (8.9)	5.2 (7.2)	0.956	0.905	1.010	0.109
LOS postoperative (days)	7.4 (10.2)	4.9 (2.7)	0.918	0.796	1.059	0.242
Wait time post-coronary angiogram (days)	35.1 (28.2)	49.7 (9.2)	1.016	<b>1.003</b>	<b>1.030</b>	<b>0.016</b>
Surgery Urgency, n (%)	1.810	0.799	4.100	0.155		
Emergent	27 (61.4%)	21 (47.7%)				
Non emergent	17 (38.6%)	23 (52.3%)				
<b>Postoperative complications, n (%)</b>						
Pleural effusion <sup>§</sup>	11 (25.0%)	0 (0.0%)	0.750	0.632	0.890	0.997
Atrial fibrillation <sup>¶</sup>	10 (22.7%)	10 (22.7%)	1.000	0.396	2.710	0.668
Weakness	4 (9.1%)	1 (2.3%)	4.300	0.461	40.118	0.121
Infection (all types)	4 (9.1%)	5 (11.4%)	0.780	0.195	3.122	0.734

Note. CABG = coronary artery bypass graft; COPD = chronic obstructive pulmonary disease; GERD = gastroesophageal reflux disease; HSN = Health Sciences North; LOS = length of stay.

\*Recreational drug use includes marijuana use.

<sup>¶</sup> LOS preoperative includes 1) patients admitted to hospital then underwent angiogram during their stay, 2) patients who have been readmitted directly post-angiogram, or 3) patients who are admitted up to 3 days preoperatively.

<sup>¶</sup>Post-operative atrial fibrillation was defined as new onset and heart rate >110 beats per minute.

<sup>§</sup>P-value not significant likely due to lack of variability in control group.

**Table 2***Readmission Characteristics*

Characteristic	Cases Readmitted ( <i>n</i> = 44)
Days to readmission from discharge, mean (SD)	18.9 (17.1)
Readmission diagnosis, <i>n</i> (%)	
Congestive heart failure	9 (20.5%)
Other	9 (20.5%)
Wound infection	7 (15.9%)
Atrial fibrillation	5 (11.4%)
Gastrointestinal bleeding	3 (6.8%)
Acute coronary syndrome	3 (6.8%)
COPD	2 (4.5%)
Failure to cope	2 (4.5%)
Pneumonia	2 (4.5%)
Syncope	2 (4.5%)
Readmission complication, <i>n</i> (%)	
Wound infection	7 (15.9%)
Other*	5 (11.4%)
Atrial fibrillation	4 (9.1%)
Pleural effusion	4 (9.1%)
Pneumonia	2 (4.5%)
Acute kidney disease	2 (4.5%)
None	20 (45.5%)
LOS of readmission, (days) mean (SD)	6.8 (5.7)
Intensive care unit stay required, yes, <i>n</i> (%)	8 (18.2%)

Note. COPD = chronic obstructive pulmonary disease; LOS = Length of stay.

\*Other included angina, acute coronary syndrome, cardiac arrest, cellulitis, hematuria, palpitations.

for readmission at 30 days post-CABG, which included heart failure (12.6%), arrhythmia (11.5%), pleural effusion (10.0%), surgical site infection (9.8%), angina (8.1%), and pneumonia (4.5%), all of which were revealed in our study.

In the literature, SDOH are rarely investigated and hence identified as factors associated with readmission following CABG. To date, authors have identified race and income/social status, where non-white race and insurance status (private insurance, Medicaid, Medicare and self-pay) were associated with readmission (Feng et al., 2018; Khoury et al., 2019; Shah et al., 2019; Shawon et al., 2021; Tam et al., 2018).

In our study, there was limited reference to race and culture, including Indigenous status, in the electronic health records. Canada lacks population data regarding race and ethnicity in health care settings (Ko et al., 2024), which impedes our understanding of the influence of race and ethnicity on health inequities. In three instances, Indigenous status was referenced in the charts, yet only determined through their insurance status of carrying valid federally-funded Non-Insured Health Benefits coverage, as outlined in the Indian Act (Government of Canada, 2019). By relying on Indigenous insurance status to determine a person's Indigenous identity, there is a greater possibility of not being able to systematically identify all Indigenous people through data included in their charts. The Rural Nursing Theory recognizes that systemic and institutional racism in health care can cause some Indigenous people to avoid public hospitals, choosing instead to seek care from Indigenous-led clinics where they feel safer and more culturally supported (Tsuji et al., 2023). Knowledge of a patient's Indigeneity can assist in the cultural tailoring of their care. For example, post-operative cardiac rehabilitation can be culturally adapted to benefit Indigenous communities (Ko et al., 2024). There is evidence suggesting that this lack of tailoring leads to some patients who identify as Indigenous, or those living in RRNCs, being less engaged in post-operative teachings and strategies to enhance recovery (Coombs et al., 2022). The SDOH framework also reinforces the need to address not only individual behaviours, but also cultural safety, access to care, and socioeconomic barriers to ensure equitable outcomes.

Although this study considered some key SDOH, income and social status—a core determinant—was not directly captured in the data. Income influences post-surgical outcomes through its impact on access to medications, transportation, housing stability, nutrition, and follow-up care. Patients in rural and remote northern communities often experience higher rates of unemployment, lower income, and reduced access to social resources, which can all impact their ability to recover post-CABG (Etowa & Hyman, 2022; CARRN, 2020).

The geographic particularities of RRNCs had important impact on our findings, in particular, distance of the patient's main residence from the hospital where the CABG took place, the population size of town of residence, and wait times. In our study, the non-readmitted group was mostly composed of patients living in small (45.5%) and medium (31.8%) population centres approximately 180 km away from HSN, while the readmitted group consisted of patients living in larger population centres (68.2%), located approximately 57 km from the hospital. While at first glance this may be surprising, it is possible that a proportion of patients in the non-readmitted group may have been readmitted to a hospital closer to their town of residence, in facilities outside HSN where we did not have access to patient charts. These patients are served by another main

**Table 3**

*Social Determinants of Health, by Readmission Status*

	Case Readmitted N = 44	Control Non-readmitted N = 44	Odds Ratio	95% Confidence Interval		p value
				Lower	Upper	
Employment and working conditions						
Employment group, n (%)						
Mining	6 (13.6%)	4 (9.1%)	0.889	0.125	6.319	0.906
Administration	3 (6.8%)	3 (6.8%)	1.524	0.305	7.604	0.608
Engineer	2 (4.5%)	1 (2.3%)	3.111	0.414	23.393	0.270
Food services*	1 (2.3%)	1 (2.3%)	0	0	0	0.999
Landscaping	1 (2.3%)	2 (4.5%)	1.333	0.057	31.121	0.858
Motor transport	3 (6.8%)	2 (4.5%)	2.667	0.158	45.141	0.497
Nursing	1 (2.3%)	1 (2.3%)	1.333	0.149	11.929	0.797
Postal services*	1 (2.3%)	1 (2.3%)	0	0	0	1.000
Teacher*	4 (9.1%)	5 (11.2%)	0	0	0	1.000
Not reported*	22 (47.7%)	24 (54.5%)	0	0	0	1.000
Private insurance, yes, n (%)	24 (54.5%)	33 (75.0%)	1.718	0.940	3.140	0.079
Physical environment						
Size of town of residence						
Large population	30 (68.2%)	10 (22.7%)	0.183	0.066	0.512	<0.001
Medium population	3 (6.8%)	14 (31.82%)		0.505	2.390	0.202
Small population	11 (25.0%)	20 (45.45%)				
Distance from HSN (km)	57.8 (80.3)	181.9 (137.3)	1.010	1.005	1.015	<0.001
Community care use	23 (52.3%)	3 (6.8%)	14.968	4.026	55.645	<0.001
Social supports						
Marital status (n, %)						
Married	26 (59.1%)	34 (77.3%)	0.255	0.048	1.367	0.111
Separated	7 (15.9%)	2 (4.5%)	1.308	0.573	1.160	0.303
Single	9 (21.5%)	0 (0%)				
Widowed	2 (4.5%)	8 (18.2%)	0.765	0.253	2.309	0.634
Discharge location*						
Home	32 (72.7%)	44 (100%)	1.375	0	0	0.170
Health care facility	6 (13.6%)	0 (0%)	18.203	0	0	1.000
Family's home	6 (13.6%)	0 (0%)				
Access to Health Services						
Patient has family health practitioner, yes, n(%)	38 (86.4%)	43 (97.7%)	0.147	0.017	1.279	0.082
Culture						
Indigenous insurance status	3 (6.8%)	0 (0%)				

Note. HSN = Health Sciences North

\*Confidence intervals estimate of 0 likely due to lack of variability in control group

hospital, which does not offer specialized cardiac care, such as coronary angiograms and cardiac surgeries. Patients in RRNCs are challenged travelling long distances for cardiac services, enduring the implications of travel, including time, financial costs, life disruptions, and missed work (Health Quality Ontario, 2017; Law et al., 2022). With greater difficulties accessing care due to geographical distance from acute and specialized care, rural residents may be more likely to dismiss early signs of postoperative complications and symptoms.

Wait times for CABG following coronary angiography and CAD diagnosis are substantially different based on geography. Patients living in a smaller population centre and not readmitted (control) waited over 49 days, while those who were readmitted waited on average 35 days. In comparison, at one Southern Ontario hospital, the average wait times for CABG post-coronary angiogram was 19 days (Ontario Health, 2024). Waitlists for cardiac consultations and subsequent cardiac surgeries are an ongoing challenge for publicly-funded systems globally (Vervoort et al., 2024). Waitlists for cardiac surgery often result in unplanned re-hospitalization and an increased risk of death (Sun et al., 2021). Law et al. (2022) conducted a retrospective analysis using a comprehensive provincial surgical wait time database in Ontario to study various surgical wait times and socioeconomic status in provincially funded health care. The authors noted that patients in rural towns waited longest for surgeries (mean 74.1 days); in comparison to the overall mean waiting time for surgery of the population (mean 62.3 days). Similarly, De Jager's et al. (2023) cross-sectional study assessed patients' timely access to nonurgent inguinal hernia repairs, cholecystectomies, hip arthroplasties, knee arthroplasties, arthroscopies, benign uterine surgeries, and cataract surgeries in Ontario from April 2013 to December 2019. They revealed that 14% of surgeries performed in RRNCs exceeded the Health Quality Ontario wait time targets in comparison to surgeries performed in urban areas (10.6%). Both the Rural Nursing Theory and SDOH help us interpret how systemic delays and geographic barriers contribute to inequities in surgical outcomes, emphasizing the need for targeted interventions that account for rural realities.

### Implications for Nursing Practice

We identified the importance of considering the SDOH in patients' journeys through CABG. These findings allow nurses caring for people living in RRNCs to be more aware of the interplay and influence of patient, procedure, and social-related factors on potential for readmission post-CABG. With this knowledge, nurses are well positioned to be able to identify patients at higher risk of readmission, so that they can receive tailored postoperative teaching, and be referred to appropriate community care and available support. Nurses can enhance pre- and post-operative teaching

and care based on the needs, locations, and lifestyles of each patient, their families, and close social supports. Eliciting and documenting SDOH in patients' charts are vital to gaining a holistic view of recovery, as factors, such as housing, income, transportation, and caregiver availability, can significantly affect outcomes (Etowa & Hyman, 2022). Designing a comprehensive discharge plan of care that integrates SDOH should be standard practice to ensure comprehensive, patient-centred care. Central to reducing readmission risk in patients living in RRNCs is health equity, defined as creating a fair health environment for all groups of people and being able to access health services without barriers, such as distance or income (Public Health Agency of Canada, 2024). Integration of the SDOH through CABG clinical pathways has the potential to enhance health equity for people living in RRNC. The Canadian Nurses Association has recognized that all nurses have "a professional and ethical responsibility to promote health equity" and "must include the social determinants of health in their assessments and interventions with individuals, families, and communities" (CARRN, 2020, pp.10). Nurses can uphold health equity by understanding patients as a whole, and capturing that understanding in their documentation (CARRN, 2020). The Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences (PRAPARE) tool is an example of a screening tool that aims to capture SDOH, developed by the National Association of Community Health Centers (2016). Freely accessible (<https://prapare.org/the-prapare-screening-tool/>) and available in several languages, this tool consists of 21 questions assessing SDOH including race/ethnicity, language, housing status, education, employment, transportation, and social integration, among others. Howell et al., (2023) conducted a cohort study testing the PRAPARE tool in an American tertiary health care environment on more than 6,000 patients. They stated this tool facilitated the collection of SDOH and can be adaptable to different clinical settings, such as the emergency department, primary care, or community clinics. There is opportunity to validate this tool in the cardiac surgery context.

Finally, nurses can turn to advocacy to ensure people living in RRNCs can easily access health services and are able to afford nutritious food and medications, regardless of where they reside, their race, or socioeconomic status (Health Quality Ontario, 2017). Advocacy for services, such as remote monitoring and post-operative telemonitoring, is crucial to support recovery for CABG patients in rural areas. These technologies facilitate virtual follow-up and enable the early detection of complications. However, limited internet connectivity, digital literacy, and infrastructure in remote regions can restrict their use. Addressing these challenges is essential to ensure equitable access to post-discharge care. Furthermore, nurses must advocate for more specialized cardiac services, such as increasing the number of sites offering coronary angiograms and CABG, closer to RRNCs. This



must be paired with comprehensive strategies to recruit and retain nurses, and other health practitioners to staff them. The Registered Nurses Association of Ontario (2015) outlined 23 recommendations to support the Government of Ontario in recruiting and retaining nurses in RRNCs, including increased access to nursing education, infrastructure renewal for community growth, and strategies to address compensation and benefit inequities for nurses in both primary and acute care sectors (Scaini & Alacon, 2023).

## Limitations

Our study is not without limitations. First, our study is an observational study and we cannot identify the causes of the revealed differences. In terms of the SDOH, we observed that readmitted patients were part of different employment groups, lived in a larger population centre, were discharged to a location other than their own home, required more community care services, and had less access to family practitioners. We can only make assumptions as to why these differences exist. For instance, the readmission rate at HSN between 2021 and 2023 was 4% lower than rates reported by other authors (CIHI, 2021; Shawon et al., 2021) and readmitted patients lived closer to the hospital in which the CABG occurred. It is possible that patients documented as non-readmitted in this study were in fact readmitted to smaller community hospitals closer to their home. We were limited to HSN's database and unable to access the medical records of smaller community hospitals in the RRNCs. Next, patients were matched based on age, sex, and year of surgery; however, other clinical variables, such as left ventricular function, number of bypass grafts, and surgical approach (e.g., off-pump CABG, minimally invasive, or traditional sternotomy) were not accounted for in the matching process. Differences in these clinical and procedural factors may influence postoperative outcomes and readmission risk, potentially introducing residual confounding and limiting the generalizability of findings. We also obtained all available data points of interest, but it remains that some data were missing from the patients' charts, a common limitation of retrospective database studies (Talari & Goyal, 2020). We did consider all forms of documentation in the electronic charts that were available to us, but we were limited to what data was available in Meditech. Furthermore, few SDOH were routinely collected and documented in the electronic medical charts. Most of the SDOH

data captured were through narrative notes suggesting that, at present, it is at the individual practitioner's discretion to capture and document them. Finally, there was a potential under-identification of Indigenous individuals, as this data relied on federal insurance records (e.g., NIHB). This may not capture patients using employer or provincial coverage, leading to incomplete representation of Indigenous identity and health care utilization.

## Conclusion

Factors for readmission post-CABG included access to health services, physical environment, and availability of services in the community, all notable within the SDOH. The findings of this study are an important step toward improving health service delivery within RRNC. To enhance holistic care for patients living in RRNCs undergoing CABG, we ought to consider the SDOH alongside patient and clinical related factors when developing plans of care for optimal outcomes. This work serves as an important stepping stone for future research, underscoring the urgent need to build more robust systems for collecting and documenting the SDOH within patient records, for greater health equity.

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## Conflicts of Interest

*None*

## Disclosure

*Associate Editor Martha Mackay handled the review process for this article. Neither Krystina B. Lewis, nor Davina Banner had access to the paper during the review process in their role as co-Editors-in-Chief or reviewers.*

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# Follow Her Heart: Addressing Gaps in Women's Heart Health Patient Resources

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## Abstract

*Cardiovascular disease is the leading cause of premature death in women globally, yet many remain unaware of their risk, and those diagnosed often lack access to gender-specific resources. This paper explores current heart health education resources tailored to women, identifying key areas needed to address educational inequities. A narrative review of scholarly and grey literature was conducted to evaluate existing resources. Three main themes emerged: Women's Heart Health Programs, Heart Health Education Topics for Women, and Women's Heart Health within Indigenous cultures. An evaluative component assessed the*

*suitability of these resources using the Patient Education Material Assessment Tool (PEMAT), with consideration for the Saskatchewan healthcare context. An advisory committee of healthcare and community stakeholders reviewed the findings. Recommendations are provided using the MAP-IT health promotion framework to address possible solutions to the identified gaps.*

**Keywords:** cardiovascular disease, heart health, women, patient education, Saskatchewan

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## Key Highlights

- Increased advocacy and improved education for clinicians and patients are vital components to addressing the growing risk of CVD among women.
- There is a current lack of women-specific resources for CVD that are not explicit to women, but may have women-specific implications, and a lack of Indigenous-specific resources.
- Online resources for women's heart health are often hard to find or navigate.
- The development and delivery of effective women's heart health educational resources delivered in a virtual format is key in addressing the prevalent status of women being “under-aware” and overcoming geographical barriers.

Cardiovascular disease (CVD), once thought to be a man's disease, is now on the rise in women worldwide, ranking as the number one cause of premature death in women around the globe, including Canada (Heart & Stroke Foundation of Canada [HSFC], 2023d; Kouvari et al., 2020; Parry et al., 2022). Not only are women more likely to die from CVD than their male counterparts, but they are also more susceptible to the negative impacts of cardiovascular risk factors (Jaffer et al., 2021). These risks and mortality rates are disproportionately experienced by women living in rural, remote, and northern areas (Jaffer et al., 2021). These disparities are further compounded in certain sub-populations (such as Indigenous, immigrant, or rural women) due to

health inequalities (HSFC, 2018, 2023d; Jaffer et al., 2021). The lack of sex- and gender-specific research on CVD and lack of inclusion of women in CVD research, as well as a lack of awareness amongst both women and clinicians, have been identified as main contributing factors to poorer outcomes for women with and at risk of heart disease (HSFC, 2018, 2023d; Norris et al., 2020). For the purposes of this review, the term “woman” will include both the sex (i.e., biological attributes including physical and physiological features, such as hormones, genes, and anatomical characteristics) and gender (i.e., sociocultural factors of constructs influencing roles, behaviours, and identities) definitions.

The aim of this narrative review is to examine the current literature on women's heart health education programs including access and availability to women-specific resources available online, with the purpose of identifying opportunities to develop contextually-relevant virtual resources for diverse populations.

## Background

Women's heart health has been recognized as an increasing area of importance in women's health over the last 25 years. Canadian leaders in cardiovascular care, such as the Heart and Stroke Foundation of Canada (HSFC), brought women's heart health to the foreground with such publications as *Ms Understood* in 2018 (HSFC, 2018). Since that time, increased advocacy and improved education regarding women's heart



health for both clinicians and patients has been acknowledged as a priority by the Canadian Cardiovascular Society (CCS), the HSFC (2018; 2023d), and the Canadian Women's Heart Health Alliance (CWHHA; CWHHA, 2023a). Furthermore, in response to the Truth and Reconciliation Calls to Action numbers 19 and 20 (Government of Canada, 2015), it is imperative that the heart health of Indigenous women be addressed in collaboration with Indigenous communities and health leaders.

The management of CVD includes drug therapy, medical intervention (e.g., coronary angioplasty), and behavioural modification to address risk factors (e.g., diet, activity, smoking cessation; Fredericks & Guruge, 2015). It is patient education, however, that is the most common intervention not only in treatment but also in prevention. Fredericks and Guruge (2015) describe patient education as “a process for providing information to patients with the goal of changing knowledge and behaviors aimed at maintaining or improving health” (p. E14).

### Why Women

With the incidence of heart disease on the rise in women globally, there is an imperative for healthcare professionals and programs to respond. Approximately 80% of heart disease in women is preventable, yet research consistently shows that women are under aware of their risks (HSFC, 2018, 2022). Most research related to heart disease has focussed on men, successfully leading to a decline in the incidence of heart disease in men. It is now well-known that women experience heart disease differently, have different risk factors, and are more at risk of developing specific types of heart disease (HSFC, 2018, 2022; Norris et al., 2020). Women experience myocardial infarction with non-obstructive coronary arteries (MINOCA) with twice the frequency of men. They are also significantly more likely to experience Takotsubo heart failure (i.e., stress-induced heart failure), and spontaneous coronary artery disease (SCAD; HSFC, 2018, 2022; Norris et al., 2020). Recognizing the disparities in heart health outcomes between men and women was the first step; now is the time to address these disparities.

### Why Saskatchewan

In Saskatchewan, 31.7% of the population reside in rural, remote, or northern communities, which is almost twice the national rate (Statistics Canada, 2024). The rate is almost double for First Nation and Metis residents, with 60% of the 180,000 Indigenous people living in rural or northern locations in Saskatchewan (Statistics Canada, 2016).

The incidence of cardiovascular disease (CVD) in women can differ by province and regions, as well as by geographic location, with notable increase in CVD risk factors and mortality in rural, remote, and northern areas (Jaffer et al., 2021). The age-standardized mortality rate of heart disease amongst women in Saskatchewan per 100,000 was 11% higher than the national rate in 2023 (Statistics Canada, 2025). These

disparities are further compounded by the health inequalities facing Indigenous women (Jaffer et al., 2021). Addressing accessibility to rural, remote, and northern areas also means addressing accessibility for Indigenous populations.

It is widely recognized that patients living in rural or remote areas have poorer outcomes in cardiovascular disease highlighting the need for improved equitable and accessible healthcare in this population (Buyting et al., 2021). The incorporation of virtual care is one way to address the inequalities of rural and remote Canadians (Buyting et al., 2021; Wilson et al., 2020). Online resources have become the first place that patients look for medical information, but also a valuable tool in the management of chronic disease (Rush et al., 2018).

The geographic and demographic landscape of Saskatchewan creates a unique opportunity within Canada, not only to address the heart health of women but also, to address the inequities facing the heart health of women in rural, remote, or northern communities and Indigenous women. Improved heart health awareness, education, advocacy, and accessibility for women in Saskatchewan in the communities that they reside in is vital to the health of Saskatchewan women, as it is to all women.

### Search Strategy

A literature search was conducted of relevant peer-reviewed journal articles and organizational websites accessed through CINAHL, the University of Saskatchewan Library search tool (USearch), and Google Scholar. In addition, a systematic search of grey literature was done for patient teaching resources and known cardiology care leaders within North America through Google. The key search terms, which were developed in consultation with the librarian and co-author used were: “heart health”, “cardiovascular health”, “women”, “females”, “patient education”, “patient teaching”, “patient information”, “heart health program”. Documents accepted for this review met the following criteria: published in the last 10 years, published in English, and freely available online.

In reviewing the articles, it was intended to encompass general findings. The selected articles reflected a combination of academic and grey literature. A total of six articles regarding women-specific heart health education initiatives were selected as appropriate: five quantitative and one qualitative. In addition, there were 40 patient-oriented resources compiled through the grey literature search. The included materials presented as print ( $n = 1$ ), informational websites ( $n = 6$ ), videos including webinars and patients' lived experience ( $n = 21$ ), and infographics ( $n = 12$ ). Of note, 15 resources included patients with lived experience. Selecting resources that provided a formative evaluation was preferred. However, this criterion could not be included as there was no formative evaluation available for any of the resources found.

Virtual resources were primarily authored by larger centres or leaders in heart health, including the CWHHA ( $n = 11$ ),



University of Ottawa Heart Institute ( $n = 9$ ), Cardiac College ( $n = 5$ ), National Collaborating Centre for Indigenous Health ( $n = 4$ ), and the HSFC ( $n = 3$ ). Each resource was independently reviewed using the Patient Education Material Assessment Tool (PEMAT) to assess for understandability and actionability, and further assessed with two questions regarding specificity to women and Indigenous women, reducing the final list to 13 (Shoemaker et al., 2024).

## Methods and Resource Evaluation

Each patient education resource was reviewed using the PEMAT, as indicated above, to assess for understandability and actionability (AHRQ, 2024). The PEMAT was chosen because it was designed to assess whether patients can understand the written or audiovisual material, and whether patients are provided the information to act on it. They were further assessed with two questions regarding specificity to women and Indigenous women (i.e., “The material addresses heart health as it relates specifically to women” and “The material provides Indigenous-specific information as it relates to women’s heart health”). The average score for understandability was 86%, and actionability was 74%. Of these resources, 83% were women-specific, with only 10% being Indigenous women-specific. All resources were available online.

Considering each resource’s scores, and acknowledging that there was duplication in some resources, the list was narrowed down to 13 resources that scored above 80% on both understandability and actionability and were women specific. The exceptions were four videos regarding Indigenous women’s heart health. One of the limitations of the PEMAT score in this setting is that it utilizes a highly biomedical worldview, which can perpetuate colonial oppression when utilized to assess Indigenous experiences, wisdom, and knowledge (Diffee et al., 2016). While these videos scored less than the 80% using the PEMAT scale, it can be argued it reflects the limitations of the PEMAT tool, not the resources, therefore these specific resources were included.

## Committee Development and Input

To increase the methodological rigour and community collaboration, an advisory committee was formed to validate the 13 resources chosen. The membership was established through previous and current working relationships to represent cardiology care, primary healthcare, and Indigenous cultural care. The final committee consisted of a cardiologist specializing in women’s heart health, a registered nurse from Saskatoon’s Women’s Heart Health Clinic, an Indigenous Elder, a Nurse Practitioner within a rural community, and a woman with lived CVD experience. Unfortunately, it was not possible to secure a Nurse Practitioner from within a northern community. The key request that was posed to the advisory committee was providing either a yes or no to the question “Is this useful for women in my community?”

for each of the 13 resources reviewed. Each response of “yes” was scored as 1, and a “no” was scored as 0. The total score was then divided by the total responses to reveal the percentage of confirmed usefulness (Table 1). Despite multiple attempts to ensure feedback, only 80% of the committee returned completed documents. These responses were then reviewed revealing the following:

There was universal agreement on usefulness for seven of the 13 resources. Some offered feedback regarding their choices with caveats of websites being difficult to navigate, or why they did not choose a specific resource, citing reasons such as excessive use of medical terminology and difficulty understanding the presenters.

It should also be noted that, at this time, we have not received feedback from our Indigenous representative, which would be of high priority for the review of all resources, but especially in the review of the *Mite Achimowin* video series. Those offering feedback acknowledged that the impact and efficacy of the video amongst Indigenous populations would potentially be impacted by the Indigenous language spoken in it.

## Informing Recommendations

To shape the recommendations for a roadmap forward, the MAP-IT framework was utilized. MAP-IT provides the

**Table 1**

*Confirmation of Usefulness of Reviewed Resources*

Resource	Confirmation of Usefulness, (%)
A Guide to Women’s Heart Health – Ottawa Heart Institute	100
Your Heart Journey – Women@Heart	100
Polycystic Ovarian Syndrome and Heart Disease – CWHHA	100
Canadian Women’s Heart Health Centre – Patient Education	100
Mite Achimowin – Heart Talk 1	100
Mite Achimowin – Heart Talk 4	100
Pregnancy Complications and Heart Health – CWHHA	100
Cardiovascular Risk Factors for Women – CWHHA	75
Cardio Oncology – CWHHA	75
Mite Achimowin – Heart Talk 2	75
Mite Achimowin – Heart Talk 3	75
Takotsubo Cardiomyopathy – Cardiac College	50

*Note.* CWHHA = Canadian Women’s Heart Health Alliance.

structure to inform and evaluate public health intervention (Office of Disease Prevention and Health Promotion [ODPHP], 2022). It is defined by the following steps: mobilize individuals and leaders within a community, assess the need of the area, plan the approach, implement the plan, and track progress (University of Kansas, 2023).

## Contextual Review

For this review, the findings were inductively derived into three themes grounded in the literature: women's heart health programs, women's heart health education topics, and women's heart health in the context of indigenous cultures. Data were systematically coded by identifying and labeling the key data pieces.

Once the essential data pieces were identified, we looked for patterns and ground the codes that shared the ideas. These patterns became the initial clusters that were named or themed. Once the initial themes were articulated, the data was reviewed once more to ensure that the integrity of the intent and context was maintained. We then looked at the opportunities to narrow the themes. It was not necessary to discard any of the original themes, but we did undertake some renaming for clarity, and finally reviewed once more to ascertain that the themes were clear and the examples were optimized.

## Women's Heart Health Programs

Specific heart health education programs have taken multiple forms including programs for menopausal women (Hassan et al., 2017), a nurse-led women's heart health clinic (Wray, 2014; 2020), electronic mobile health intervention (Sengupta, et al., 2020), sex-specific cardiac risk factor management (Low et al., 2018), and education on myocardial

infarction symptoms in women aimed towards rural women (Kalman et al., 2018; See Table 2). Improved self-efficacy, increased knowledge and awareness, and decreased depressive symptoms occurred as a result of the mobile health intervention (Sengupta et al., 2020) and mosque-based physical activity intervention (Banerjee et al., 2017). Providing self-referral options also led to improved patient enrollment and commitment (Wray, 2014).

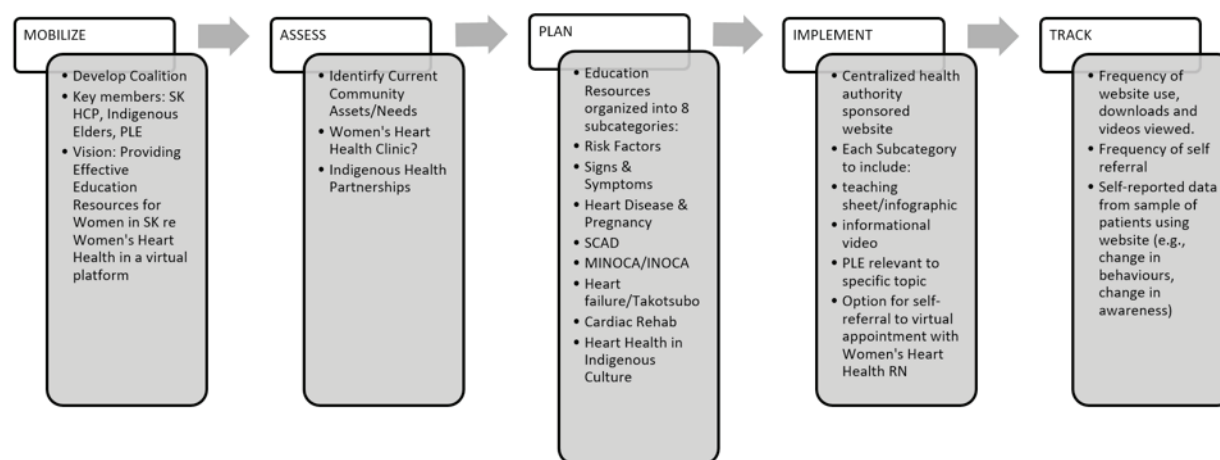
Structured programs, including the mosque-based physical activity intervention, the heart health education for menopausal women, and sex-specific cardiac management, addressed specific cardiovascular risk factors, such as activity levels, diet, and smoking, with improved outcomes on cardiac end points, such as blood pressure, waist circumference, and cholesterol levels. However, they were not statistically significant (Banerjee et al., 2017; Hassan et al., 2017; Low et al., 2018). Statistically significant improvements were noted in both exercise tolerance and attitudes toward physical activity (Banerjee et al., 2017).

Nurse-led interventions, as seen in the nurse-led women's heart health clinic, revealed statistically significant improvements in blood pressure, cholesterol levels, and absolute CVD risk (Wray, 2014). This intervention offers a strong mechanism for success in addressing the educational gaps regarding patient-specific education. There is also the opportunity to engage nurse-led interventions in primary prevention in addition to secondary prevention and chronic disease management. Nurse-led interventions have been found to have a reduction in cost impacts to the healthcare system, while improving health outcomes (Browne et al., 2015; Salamanca-Balen et al., 2017).

## Women's Heart Health Education Topics

**Figure 1**

*Follow Her Heart: A MAP-IT Approach*



*Note:* SK = Saskatchewan; HCP = healthcare provider; PLE = personal learning environment; SCAD = spontaneous coronary artery dissection; MINOCA = myocardial infarction with no obstructive coronary artery disease; INOCA = ischemia with no obstructive coronary arteries.

**Table 2***Summary Table of Women-Specific Heart Health Education Initiatives*

Author(s)/Year/Title/ Country	Purpose	Sample/Design	Data/Tools	Results
Banerjee et al. (2017). A pilot examination of a mosque-based physical activity intervention for South Asian Muslim women in Ontario, Canada	"To examine the feasibility, acceptability and effectiveness of a mosque-based physical activity program for South Asian Muslim women in Canada." (p.349)	19 women; community-based pilot project, single group intervention, pre-and post-intervention test outcomes evaluation.	Duke Activity Status Index; International Physical Activity Questionnaire	Increase in self-efficacy scores, and the importance of engaging in regular physical activity; fewer participants classified as inactive.
Hassan et al. (2017). Effect of health education program on cardiovascular risk factors among menopausal women in Malaysia. Malaysia	"To evaluate the effectiveness of health education program on cardiovascular risk factors among perimenopausal women in Kelantan, Malaysia." (p.51)	64 women, age 45–55. Randomized control trial	Intervention group received multiple forms of health education (workshops, lectures, counselling), control group routine advice	Significant reduction in blood pressure in both groups only.
Kalman et al., (2018). Educating rural women about gender specific heart attack and prodromal symptoms. United States of America	"To test the efficacy of using acronyms to educate rural women on female MI and prodromal symptoms as well as the appropriate response to these symptoms and to assess if knowledge gained was sustained for a 2-month period." (p.113)	137 rural women. Age 25–90 Quasi-experimental design with two groups with site randomization of educational intervention.	Matters of Your Heart Scale version 2	No statistically significant difference in knowledge.
Low et al. (2018). The women's heart health program: A pilot trial of sex-specific cardiovascular management. Singapore	"To compare the clinical outcomes (CV risks factor control and CV event rates), quality of life and the self-reported knowledge, attitudes, intentions and practices amongst women already known to have CV disease, when managed" in sex neutral vs sex-tailored women's heart health program." (p.2)	100 women. Age 21–99. Randomized control trial.	CV risk markers (BMI, SBP, HgbA1c, HDL, LDL)	No significant difference in CV risk markers between groups, quality of life knowledge, attitudes, intention and practices.
Sengupta et al. (2020). A mobile health intervention system for women with coronary heart disease: Usability study. United States of America	"To examine the usability of a prototypic mHealth intervention designed specifically for women with CHD...and the influence on selected health behaviours and psychological characteristics of participants." (p.e16420)	10 women; Single-group, pre-intervention test, post-intervention test design	System usability scale; Eating Habits Confidence Survey; Exercise Confidence Survey, Perceived Stress Scale; Rapid Eating Assessment for Participants–Short Form; International Physical Activity Questionnaire–Short Form Patient Health Questionnaire–9	All participants completed study. Statistically significant improvements in waist circumference, weight, and BMI. Improved depressive symptoms.
Wray, W. (2014). Preventing Cardiovascular Disease in Women. Canada	Review of Women's Healthy Heart Initiative clinic after initial 3 years of operation	Retrospective review of aggregate clinical outcomes of 317 clinic patient records.	Clinical outcomes. Patient satisfaction survey.	Decrease in average BMI; reduction in BMI and LDL levels with pharmacologic and lifestyle therapy; patients appreciated self-referral.

*Note.* CV = cardiovascular; BMI = body mass index; SBP = systolic blood pressure; HgbA1c = test for average blood sugar level; HDL = high-density lipoprotein; LDL = low-density lipoprotein; CHD = congenital heart disease.

The sub-themes of specific topics within this theme most frequently addressed by the reviewed resources were women-specific risk factors ( $n = 11$ ), heart disease symptoms ( $n = 7$ ), pregnancy and heart disease ( $n = 4$ ), SCAD ( $n = 4$ ), MINOCA or ischemia with non-obstructive coronary arteries (INOCA;  $n = 4$ ), viewing heart disease with an Indigenous lens ( $n = 5$ ), heart failure ( $n = 3$ ), takotsubo cardiomyopathy ( $n = 3$ ), and cardiac rehabilitation ( $n = 2$ ). See Table 3. Some resources covered multiple topics (i.e., women-specific risk factors and pregnancy and heart disease), while others were more singularly focused.

Risk Factors

Risk factors specific to women was the most prominent education topic discussed, being reflected in 11 of the education resources. These are important to discuss, as they constitute a longer list of contributing influences for women than men. Not only do women need to be aware of the “classic” risk factors, such as high blood pressure, elevated cholesterol, and smoking, but they also need to be aware of the impacts of potential pregnancy complications (e.g., pre-eclampsia), auto-immune diseases, and polycystic ovarian syndrome (PCOS), which increase women’s risk of heart disease, as well as how these evolve through the life-course of women (Canadian Women’s Heart Health Centre [CWHHC], 2022a; Norris et al., 2020).

Heart Disease Signs and Symptoms

Another distinguishing element of heart disease in women is how their symptoms present (CWHHC, 2022c; Norris et al., 2020). While sharp or crushing chest pain can be reported by both women and men, there are a number of other symptoms women experience, often presenting as a constellation of less specific symptoms (CWHHC, 2022c; Ottawa Heart Institute, 2023). These can include shortness of breath, chest pressure, extreme sweating, stomach pain/nausea/indigestion. Some of the symptoms specific to women can include profound fatigue, lightheadedness, generalized anxiety, flu-like symptoms, sleep disturbances, and palpitations (CWHHC, 2022c; CardioSmart, n.d.; Ottawa Heart Institute, 2023). Providing tools for women to identify their symptoms is imperative in overcoming the vulnerabilities of being under-aware and underdiagnosed, and can ultimately save lives (CWHHC, 2022c; American College of Cardiology Foundation [ACCF], 2024).

MINOCA/INOCA

MINOCA is defined as a myocardial infarction “without significant coronary artery stenosis (i.e., >50%) on coronary angiography” (Pacheco et al., 2024). This includes a heterogeneous group of atherosclerotic (e.g., plaque rupture, plaque erosion, calcific nodules, and coronary microvascular dysfunction) and nonatherosclerotic (e.g., SCAD, embolism, and vasospasm) conditions that result in myocardial

Table 3  
Topics of Women’s Heart Health Education Resources and Frequency

Topic	Frequency (n)
Women Specific Risk Factors	11
Heart Disease Symptoms	7
Heart Disease with an Indigenous Lens	5
SCAD	4
MINOCA/INOCA	4
Heart Failure	3
Takotsubo	3
Cardiac Rehabilitation	3
Autoimmune Disorders and Heart Disease	2
PCOS and Heart Disease	2
Atrial Fibrillation	1
Cardio-oncology	1

Note. SCAD = spontaneous coronary artery dissection; MINOCA = myocardial infarction with no obstructive coronary artery disease; INOCA = ischemia with no obstructive coronary arteries; PCOS = polycystic ovary syndrome.

infarction (Pacheco et al., 2024, Health e-University, 2023a). Up to 30% of women experiencing chest pain are actually experiencing MINOCA due to dysfunctional, narrowing, blocked, or spasming coronary microvasculature (CWHHC, 2022d). Risk factor management, symptom management and psychosocial support are key to treating this diagnosis (CWHHC, 2022d).

SCAD

As mentioned above, SCAD is one of the non-atherosclerotic presentations of MINOCA. It is not specific to women; however, 90% of SCAD patients are women, while accounting for 35% of acute coronary syndrome in women under the age of 50 (Clark et al., 2021; Gilhofer & Saw, 2019; Hayes et al., 2018). SCAD is also not associated with traditional cardiac risk factors (Clark et al., 2021) and can be triggered by emotional events, physical stress and even pregnancy (HSRC, 2023a). This contributes to significant mental health impacts for women who have experienced SCAD (Hayes et al., 2018). Despite the disproportionate number of women experiencing SCAD, there are limited resources directed specifically to women (CWHHC, 2022b; Health e-University, 2023; HSFC, 2023a).

Heart Failure/Takotsubo

Heart failure affects both men and women; however, women are more likely to experience heart failure with



**Table 4***Top Rated Online Resources Reviewed with PEMAT Scores and Inclusion of Women-Specific and Indigenous-Specific Information*

Document Name	PEMAT Understandability Score (%)	PEMAT Actionability Score (%)	Women-Specific	Indigenous-Specific
A Guide to Women's Heart Health (University of Ottawa Heart Institute, 2023)	100	100	x	
Cardio Oncology (CWHHC, 2023c)	86	100	x	
Cardiovascular Risk Factors for Women (CWHHC, 2022a)	93	100	x	
Heart Attack Symptoms Most Often Reported by Women (CWHHC, 2022c)	100	100	x	
Canadian Women's Heart Health Centre - Patient Education (University of Ottawa Heart Institute, 2025)	100	100	x	
Mite Achimowin - Heart Talk 1 (NCCIH, 2019a)	71	33	x	x
Mite Achimowin - Heart Talk 2 (NCCIH, 2019b)	71	33	x	x
Mite Achimowin - Heart Talk 3 (NCCIH, 2019c)	71	33	x	x
Mite Achimowin - Heart Talk 4 (NCCIH, 2019d)	71	33	x	x
Polycystic Ovary Syndrome and Heart Disease (CWHHC, 2023b)	80	100	x	
Pregnancy Complications and Heart Health (CWHHC, 2022d)	93	100	x	
Takotsubo Cardiomyopathy (Health e-University, 2023c)	100	100	x	
Your Heart Journey (WomenHeart, 2025)	100	100	x	

Note. PEMAT = patient education materials assessment tool; CWHHC = Canadian Women's Heart Health Centre; NCCIH = National Collaborating Centre for Indigenous Health.

preserved ejection fraction (HFpEF; CWHHC, 2023b). Women also have unique risk factors to heart failure, including hypertensive disorders in pregnancy, PCOS, peripartum cardiomyopathies, and chemotherapy induced cardiomyopathies specific to treatments utilized more in women (e.g., chemotherapy for breast cancer treatment) (CWHHC, 2023b). The biggest strategy for managing heart failure in women is seeking prevention through early and appropriate treatment of risk factors (CWHHC, 2023b).

Takotsubo is a temporary stress-induced cardiomyopathy with 90% of cases occurring in women ages 58–75 (Health e-University, 2023c). This is an important area of women-specific heart health, given such high incidence. It also highlights the importance of addressing stress management for women.

### Pregnancy and Heart Health

Pregnancy is frequently described as a “stress-test” on the heart (CWHHC, 2022e). Blood pressure complications (e.g., gestational hypertension and pre-eclampsia) and gestational diabetes are linked to increased risk of heart disease later in life, such as heart failure and microvascular disease including SCAD (CWHHC, 2022b, 2022e, 2023b). Women understanding the presence of increased risk associated with these complications of pregnancy can not only increase their awareness but also encourage advocacy for their own health.

### Cardiac Rehabilitation

Cardiac rehabilitation is known to benefit CVD patients significantly, through improved physical and psychological wellbeing and increased psychosocial support (Heald et al., 2021; Neubeck et al., 2022). Women who participate in cardiac rehabilitation live longer and are less likely to return to hospital (CWHHC, 2023). Ensuring women are aware of the benefits of accessibility of cardiac rehabilitation is imperative in providing full cardiac treatment to women living with CVD.

### Women's Heart Health in the Context of Indigenous Culture

Historically, First Nations peoples have approached heart health holistically, recognizing that the physical, emotional, and spiritual needs of not only the individual but also the community were integral in heart health (Fontaine et al., 2019). The impacts of colonialism and the dominance of a biomedical worldview have silenced First Nations ways of knowing and sharing of that knowledge (Fontaine et al., 2019). Lifestyle-related risk factors (e.g., diabetes), experiences within the health care system, relationships with children and grandchildren, and residential schools are all identified as impacting the health of the *mite* (heart; Fontaine et al., 2019). *Mite achimowin*, or Heart Talk from the Swampy

Cree dialect, provides an opportunity for Indigenous women to use their traditions of oral history and story telling to speak to the importance of heart health, and elevate Indigenous wellness practices (Fontaine et al., 2019). This approach moves away from the biomedical worldview, while honouring the idea of two-eyed seeing, recognizing there are multiple ways of understanding the world including Indigenous and biomedical knowledge (Martin, 2012; HSFC, 2023c).

## Identified Gaps

Current resources provide a strong foundation of what to include in shaping the resources of Saskatchewan healthcare providers (HCPs). However, there are some notable gaps. While multiple resources address various heart diagnoses, there is a lack in providing women-specific instruction for cardiovascular diseases that are not explicit to women but may have women-specific implications from a gender or social perspective, such as SCAD, MINOCA, and cardiac rehabilitation. We know that men also experience SCAD and MINOCA, but the prevalence is higher in women (Gilhofer & Saw, 2019). Men are also more likely to participate in cardiac rehabilitation than women, which is often related to social factors impacting women, such as being the primary caregiver in a family (Gilhofer & Saw, 2019; Neubeck et al., 2022).

The ease of access to resources was sometimes limited, requiring multiple search terms, further scrolling, and sifting to find credible resources. The exception was the CWHHC, whose website was the most user friendly.

The cultural aspects as reflected above were derived from the literature as per the narrative review approach. Admittedly there are many opportunities to expand on the context of Indigenous Culture, but it is outside the scope of this initial narrative review. It was found that Indigenous-specific resources were significantly lacking and challenging to find. There is an opportunity for further inquiry into Indigenous-specific resources and to provide easier access, especially from more well-known heart health experts (e.g., HSFC and CWHHC), and more robust resources.

## Recommendations

Through review of the literature and resources, it is recommended that women-specific educational resources be developed to address the multifaceted education needs regarding women's heart health and delivered via a centralized virtual platform to overcome the geographic challenges of a diverse population in urban, rural, remote and northern areas as seen in Saskatchewan. The following section describes a roadmap to the development, organization, and distribution of these resources utilizing the MAP-IT framework (ODPHP, 2022) as defined by mobilizing individuals and leaders within a community, assessing the need of the area, planning the approach, implementing the plan and tracking progress (University of Kansas, 2023).

## Mobilize

This effort represents the first steps in mobilizing and developing a coalition of interested parties within the broader community of Saskatchewan. Including key individuals in the advisory group is the first step in developing a larger coalition. It is these same roles that would need to be represented in the development of Saskatchewan-based resources. In the future, this group could develop and clarify the vision to define the plan of action further. For the purposes of this paper, the vision identified is providing effective education resources for women in Saskatchewan regarding women's heart health within a virtual platform.

## Assess

The next step would be to assess the community needs and assets. Review of the literature has provided direction in what topics would need to be addressed and potentially how to disseminate the information. An environmental scan of the province's current services would be required to identify if there were already programs in place and in what capacity they were addressing topics within women's heart health. For example, are there nurse-led women's heart health clinics available in Saskatchewan? What is the current mode of education, if any, regarding women's heart health? What partnerships with Indigenous communities are currently in place regarding heart health management? It is the involvement of the community stakeholders and heart health champions that would be crucial to the gathering of this data.

## Plan

The action plan is defined by setting specific objectives and strategies to accomplish them. These objectives are best informed by evidence-based interventions and engagement with the stakeholder group identified during the 'mobilize phase' (ODPHP, 2022). The review of literature completed for this narrative review would continue to inform next steps considering the assessment of what is currently in place and what gaps exist.

The significant rural, remote, and northern population in Saskatchewan potentiates the need/desire for a virtual tool kit format. This format provides ease of access to information to all women in the province from trusted resources, independent of their proximity to clinical care or actual geographical location.

Utilizing the current data available it is recommended that patient education be organized into the following eight categories: risk factors; heart disease signs and symptoms; SCAD; MINOCA/INOCA; heart failure/takotsubo; heart disease and pregnancy; cardiac rehabilitation; and heart health in Indigenous culture.

Health promotion that is rooted within the biomedical world is more likely to be ineffective within Indigenous populations (Diffey et al., 2019). In addressing heart health within Indigenous cultures, the voice of elders within the community needs to be included. It is imperative to collaborate

with Indigenous HCPs and acknowledge Indigenous ways of knowing and sharing how to care for heart health (Fontaine et al., 2019, Diffey et al., 2019).

## Implement

Implementation is beyond the scope of this paper, but it is recommended that a centralized website be created, which would include a range of options/topics. For example, it might incorporate the previously described eight subcategories or modules as listed above, consisting of a teaching sheet/infographic ideally in multiple languages including, but not limited to English, French, Dene, and Cree. Additionally, informational videos featuring medical/nursing heart health experts speaking to select topics could provide critical information in patient-friendly language with the explicit intent to provide meaningful, understandable, and actionable information. The site may also include patients with lived experience relevant to the specific category sharing their stories.

Noting the prior success of nursing-led heart health programs and self-referral, it is recommended there be an option for a virtual appointment with a women's heart health nurse. Providing a self-referral option within the virtual platform supports an increase in access to appropriate care for those in rural, remote, and northern communities.

## Track

Once implementation has occurred, tracking will be required to provide consistent feedback regarding the progress and efficacy of the intervention. Regular and accurate evaluation allows improvement to be acknowledged, and adjustment of the intervention(s) being assessed. Suggested tools for tracking would be data around website use, frequency of self-referral for a virtual nursing assessment, and self-reported data from a sample of patients using the website (e.g., change in behaviour, change in awareness).

Of note, ensuring appropriate data collection and tracking was in place would not only aid in providing effective education tools, but also have the potential to address the paucity of research evidence regarding women's heart health patient education interventions. Collecting data with the intention of publishing the results could supply other HCP and health authorities with evidence-based approaches to patient education, and evidence-informed quality improvement initiatives.

## Limitations

There was a lack of scholarly literature regarding patient-specific education regarding women's heart health. This gap is consistent with the messaging of the "unders" of women's heart health being under-researched, under-diagnosed, under-treated, under-supported, and under-aware (HSFC, 2018). Much of the limited research on women's heart health was regarding education directed toward health professionals, such as the comprehensive CWHHA's Heart Health Education Course (CWHHA, 2023c). Educating

healthcare providers is a vital step toward addressing the "unders" previously listed and improving heart health outcomes for women. It is the dearth of scholarly literature on *patient-focussed education* that should now inform our next steps. Availability of women-specific cardiology care is limited across the country. This makes it challenging to identify how creating the aforementioned resources would be supported financially and sustainably. Identifying women's heart health as a provincial health care issue provides the opportunity to pursue funding from the provincial health authority and to utilize current infrastructure to support this endeavour. The Saskatchewan Health Authority recently launched its first Women's Heart Health Clinic in Saskatoon. It is the clinicians within this clinic that would need to lead and develop the resources described above, and to request funding for ongoing support.

## Conclusion

The issue of improving cardiac care and outcomes for women is coming to the forefront of healthcare, thanks to the work of multiple leaders in cardiology care, such as the Canadian Cardiovascular Society, the Heart & Stroke Foundation of Canada, the American College of Cardiology, and Canadian Women's Heart Health Alliance. As opportunities are created for HCPs to increase their knowledge of women and heart disease, there must also be opportunities for women to increase their knowledge. Providing effective health information and health promotion activities that are easily accessible for women at all stages of life and in various geographic locations is key in addressing the prevalent status of women being "under-aware."

By informing the framework for a virtual education toolkit on women's heart health, this important strategy for healthcare education, prevention, and advocacy can be delivered by healthcare team members to the target population, regardless of location, including urban, rural, or northern reach. This approach specifically addresses the inequalities experienced by women within cardiology care as well as the limited access to care for Saskatchewan residents due to geography and Indigeneity. This toolkit would empower communities to address these inequalities for women closer to home and ensure that women know that the health of their heart matters to them, their families, and their communities.

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# Supports for Parents of Infants Diagnosed with a Congenital Heart Defect: A Narrative Synthesis of Qualitative Research

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## Abstract

Parents of infants diagnosed with a congenital heart defect (CHD) often experience an overwhelming emotional journey, characterized by anxiety, stress, and role strain. This study examines the informational, emotional, and practical supportive care needs of parents whose infants are diagnosed with a CHD in hospital, at birth. Employing a secondary analysis of qualitative literature in the form of a narrative synthesis, this research categorizes parents' needs into three types: (1) informational, where parents often feel overwhelmed by medical terminology and desire

clear guidance; (2) emotional, where parents require empathy and understanding from healthcare providers and benefit from peer support; and (3) practical, highlighting parents' need for assistance with daily responsibilities and self-care. Findings from this synthesis emphasize the role of nurses in meeting these needs through comprehensive education, compassionate care, and practical resources. Thus, nurses can collectively help reduce parental anxiety and foster a supportive environment for families.

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## Introduction

Congenital heart defects (CHDs) are the most common type of birth defect, affecting 12.1 per 1,000 births in Ontario each year (Miao et al., 2023). Global estimates of CHDs at birth are as high as 1.8 per 100 live births (GBD 2017 Congenital Heart Disease Collaborators, 2020). Congenital heart defects are structural abnormalities of the heart present at birth, which can affect both the heart muscle and the surrounding vessels, necessitating multiple surgeries, hospital stays, medical interactions, and a lifelong commitment to care management (Buratto & Kostantinov, 2016; Rao, 2024). The etiology of CHDs is multifactorial, involving genetic, environmental, and possibly maternal health factors (Sun et al., 2013). Genetic contributions can include chromosomal abnormalities and single-gene mutations, while environmental factors may involve maternal exposures to certain medications, alcohol, or infections during pregnancy.

Congenital heart defects can be diagnosed prenatally, at birth before discharge (neonatal), and after discharge from hospital, where better outcomes have been reported with prenatal diagnosis (Wren et al., 2008). Severe CHD conditions typically present at birth with cardiorespiratory decompensation evidenced by cyanosis (Pavlicek et al., 2021; Wren et al., 2008; GBD 2017 Congenital Heart Disease Collaborators, 2020). Pavlicek et al. (2021) report that 40% of CHDs are

diagnosed prenatally during the 18- to 20-week ultrasound. If not detected prenatally, 95% of cyanotic CHDs, are identified within the first week of life, due to severe symptoms. Additionally, 66% of acyanotic heart defects, such as ventricular septal defects, coarctation of the aorta, and pulmonary stenosis, are diagnosed within the same timeframe when infants fail pulse oximetry screening (Pavlicek et al., 2021; Jain et al., 2022). Thus, diagnosis of CHDs can occur in hospital through pulse oximetry screening (Ewer et al., 2012; Martin et al., 2020; Peterson et al., 2014). This non-invasive test measures blood oxygen saturation (SpO<sub>2</sub>) in the right hand and foot, where differences between these readings may indicate abnormal blood flow, such as right-to-left shunting (Ewer et al., 2012). Further diagnostics, such as an echocardiogram, can then be conducted to evaluate the heart's structure and function (Ewer et al., 2012).

Treatment for CHDs varies depending on the type and severity of the defect. Some CHDs may resolve spontaneously or require minimal medical intervention, while others require complex surgical procedures and long-term medical management to improve cardiovascular function (Sun et al., 2013). Effective management and recovery require a multidisciplinary approach, including ongoing monitoring and supportive care from nurses, who play a crucial role in patient education and health promotion (Wilandika et al., 2023; Machado Amazonas et al., 2023).

When parents are informed their infant has been diagnosed with a CHD, they often experience a rollercoaster of emotions, such as shock, fear, and anxiety (Wei et al., 2016). The initial diagnosis often shatters parental expectations of having a healthy baby, leading them to experience grief, guilt, and helplessness (Nayeri et al., 2021; Wei et al., 2016). This emotional distress is intensified by the uncertainty of their child's prognosis and the complexity of the medical information they must process (Tallon et al., 2015; Wei et al., 2016). These heightened levels of anxiety and stress have caused parents to feel their role has altered to a focus on understanding complex medical information, which has been shown to disrupt parent-infant bonding and attachment (Vainberg et al., 2019). The feeling of the need to intensely monitor their infant can also lead to parental role strain and social isolation, further exacerbating their stress and emotional burden (Vainberg et al., 2019).

The birth of a child with a CHD affects the dynamics and relationships among the entire family (Machado Amazonas et al., 2023). Siblings may feel neglected, and marital relationships can be strained due to the emotional and physical demands of caring for the affected child. Furthermore, family routines and dynamics often need to be adjusted to accommodate the child's medical needs, which can include parents leaving employment and having no time for leisure activities (Machado Amazonas et al., 2023). Work interruptions further disrupt family dynamics as 83.4% of mothers in one study reported financial strain, describing a constant struggle to meet expenses and often living paycheck to paycheck (Tallon et al., 2015). Therefore, the impact of lost wages can exacerbate stress within the family, affecting both immediate family dynamics and long-term stability.

Parents frequently report feeling anxious and unsupported while navigating their child's care (Machado Amazonas et al., 2023). Higher levels of anxiety are linked to reduced knowledge and understanding, decreasing parents' confidence in making decisions about their child's care (Tallon et al., 2015). However, too much medical information caused parents to feel overwhelmed and vague information left them with many questions, resulting in feelings of stress and anxiety. In the study by Azhar et al. (2018), the information provided by healthcare professionals was deemed unclear in 30.8% of cases and not helpful for parents to care for their children in 29.2% of cases. Additionally, 56.7% of caregivers declared they had not received education about the long-term management of their child's disease and 69.2% declared they had not received education about the side effects or potential complications of the recommended treatment (Azhar et al., 2018). Thus, support from nurses can have an impact on alleviating negative emotions and improving parental confidence in making care decisions for their children (Tallon et al., 2015; Vainberg et al., 2019).

Since many caregivers report not receiving sufficient education about their infant's diagnosis and treatment, it is

crucial to understand their supportive care needs and determine the optimal timing for nurses to provide education (Azhar et al., 2018). The effectiveness of educational interventions in decreasing parental anxiety has been demonstrated in the literature, with lower anxiety levels reported in parents who received structured educational support (Simeone et al., 2017). In a study by Werner et al., 2019, it was evident that the quantity and quality of information provided to parents preoperatively significantly influenced their anxiety levels. Detailed discussions with parents about their child's disease, its etiology, and potential complications of surgical intervention for more than 10 minutes, also reduces anxiety levels in parents (Werner et al., 2019; Azhar et al., 2018). Visual aids, such as photographs from their child's echocardiogram, further enhances understanding and reduces caregiver anxiety (Azhar et al., 2018).

## Objective

Despite existing research on parental experiences when their infant has been diagnosed with a CHD, gaps remain in understanding the informational, emotional, and practical needs of parents during the diagnosis and treatment stages after birth, during the neonatal period prior to hospital discharge. Although existing research highlights the benefits of education and peer support, it does not discuss strategies to inform nursing practice to support parental needs (Machado Amazonas et al., 2023). To bridge this gap, the present study seeks to deepen understanding of parental experiences during the postnatal hospitalization period following a CHD diagnosis. By synthesizing these experiences, the study aims to generate practice-informed insights that can guide nursing interventions and enhance family-centred care.

## Methods

### Methodology

To address the identified problem, a review of qualitative evidence was conducted in the form of a narrative synthesis (Heaton, 2008). This process involved systematically integrating findings from multiple studies, identifying patterns, themes, and relationships within the data to generate a cohesive summary and suggest the direction for future research (Heaton, 2008). This narrative synthesis aimed to gain insights into the informational, emotional, and practical needs of parents of infants with CHDs, as well as to identify strategies that will inform nursing practice to support these families better. By synthesizing findings from multiple studies, this approach allowed for a comprehensive understanding of parental support needs without the constraints of recruiting participants and conducting interviews (Heaton, 2008).

To ensure methodological rigour of this narrative synthesis, the Scale for the Assessment of Narrative Review Articles (SANRA) reporting guidelines were followed (Baethge et al., 2019). This tool facilitated the appraisal of six domains,



including justification of the review’s importance, specification of research aims, and critical interpretation of findings, ensuring that the synthesis meets standards of a narrative review (Baethge et al., 2019).

### Theoretical Framework

Social support theory is a middle-range theory that emphasizes the importance of informational, emotional, and practical assistance in helping individuals cope with stress (Chouhy et al., 2020; Evans et al., 2022). According to the theory, individuals with high levels of social support are thought to be protected from the negative effects of stress (Langford et al., 1997). Informational support refers to the advice, explanations, and educational resources that can help people make decisions in a time of stress (House, 1981; Langford et al., 1997). Emotional support includes the provision of empathy, love, and trust for reassurance to foster feelings of being valued and understood. Instrumental support, also referred to as practical support, looks at tangible goods and services, such as filling basic physiological needs or accessing care (House, 1981; Langford et al., 1997). Nurses are vital in providing comprehensive support to parents, offering clear information, emotional comfort, and practical help, such as coordinating follow-up care (Fuglsang et al., 2023). Failure to address these needs can result in long-term stress and negative health outcomes for both the parents and their children (Kumar et al., 2019). By recognizing and addressing these supportive care needs, nurses can reduce parental stress, improve family well-being, and promote better health outcomes (Wilandika et al., 2023). Therefore, social support theory was used in this narrative synthesis to conceptualize parental experiences and needs.

### Search Strategy

A comprehensive literature search was conducted using the following electronic databases: PubMed, CINAHL, ScienceDirect, and Web of Science. The search terms used for each database frequently included “congenital heart defect”, “parents”, “experiences” “infants” “surgery” and “qualitative”, with a date range of 2014–2024 (Table 1). The search results were imported into Covidence to filter and screen for appropriate studies (Figure 1). The focus was on qualitative studies that explored the experiences of parents with infants diagnosed with CHDs during the neonatal period—while in hospital after birth. Studies containing direct quotes from interview transcripts of parents with infants diagnosed with CHDs in hospital after birth, including those that required treatment in hospital, were selected for analysis. Direct quotations were of particular interest in this synthesis, as they encapsulated the experiences of the interviewees, providing insight into their lived realities through their own words. A hand search was also conducted to ensure relevant pieces of literature were captured. One study conducted in the United Kingdom was identified and included for analysis. A total of 7 studies were included by the following authors: Gaskin et al. (2021), Gramszlo et al. (2020), Nayeri et al. (2021), Ni et al. (2019), Thomi et al. (2019), Vainberg et al. (2019), and Wei et al. (2016). In instances where mixed-methods studies were included, only the qualitative data derived from semi-structured interviews was extracted and analyzed. This data, typically presented as participant quotations, was treated equivalently to those from purely qualitative studies. This approach ensured consistency in the synthesis process, with all qualitative

**Table 1**

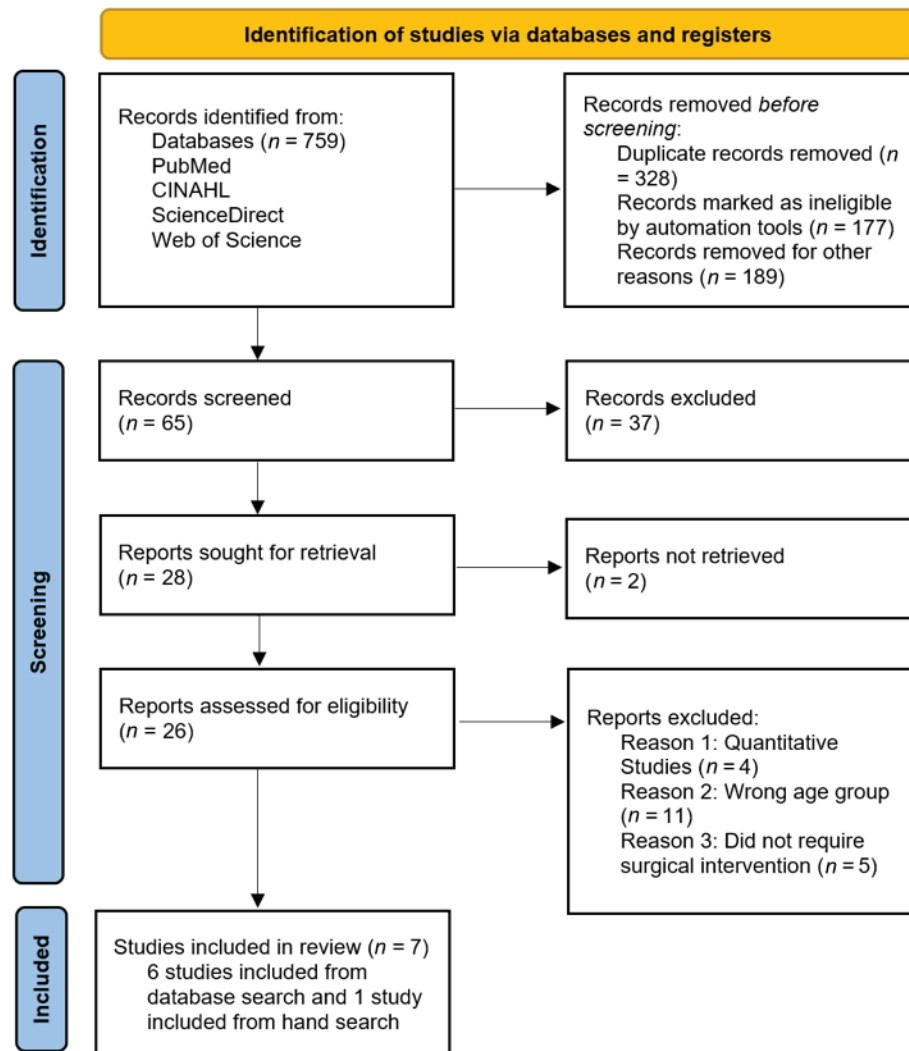
*Search Strategy*

Database	Year	Search Terms	Number of Results	Article(s) Selected
Web of Science	2014–2024	“parent experience”, “congenital heart disease”, “qualitative”	145	Nayeri et al. (2020)
CINAHL	2014–2024	“parental experience”, “congenital heart defect OR disease”, “surgery”, “qualitative”	17	Thomi et al. (2018)
PubMed	2014–2024	“parents”, “experience”, “congenital heart”, “surgery”, “qualitative”	43	Vainberg et al. (2019) Ni et al. (2019)
PubMed	2014–2024	“support”, “parents”, “infant”, “hospital”, “congenital heart disease OR defect”	163	Gramszlo et al. (2020)
PubMed	2014–2024	Hand search	-	Gaskin et al. (2021)
ScienceDirect	2014–2024	“parents”, “experiences”, “infants”, “congenital heart defect”, “qualitative”	391	Wei et al. (2016)



**Figure 1**

*PRISMA Tool for Identification of Qualitative Studies*



findings—regardless of study design—subjected to the same analytic criteria and interpretive rigour.

### Data Analysis

Data analysis was conducted using Braun and Clarke's (2019) codebook thematic analysis, guided by social support theory as the coding framework (Braun & Clarke, 2021; Chouhy et al., 2020; Evans et al., 2022). This approach enabled the early identification of themes related to the categories of informational, emotional, and practical support. Articles were read in entirety to become familiarized with themes and findings, which were compiled in a summary table of major findings (Table 2). The methodological quality of included studies was appraised using the 2021 version of the Joanna Briggs Institute (JBI) six-item checklist (Aromataris & Munn, 2020). This version was selected due to its capacity to generate categorical ratings of high, medium,

or low quality, thereby facilitating comparative assessment across studies. In contrast, more recent iterations of the JBI tools do not provide such scoring distinctions, making the 2021 checklist more suitable for the purposes of this review.

During the coding process, quotes from interview transcripts in the selected studies were highlighted in different colours based on which category of social support theory they aligned with. Quotes that directly or indirectly conveyed parental needs across the three support categories were included in the analysis. This use of social support theory as a coding framework to understand the supportive care needs of parents of infants diagnosed with a CHD has yet to be done by another study. Therefore, the findings provide a deeper understanding of the supportive care needs of parents, leading to the development of evidence-based recommendations for nursing practice.

**Table 2***Summary of Articles in Analysis*

Authors, year of publication, origin/country of study	Research Question or Objective (Phenomena and Population)	Qualitative Methodology	Major Findings	Quality Appraisal JBI
(Gaskin et al., 2020) United Kingdom	<b>Objective</b> To examine parents' experiences during the transition from hospital to home with their infant following stage 1 cardiac surgery for complex congenital heart disease.	Mixed methods feasibility study including both quantitative and qualitative methods. A 6-phased approach to thematic analysis was used to analyze qualitative data. Sample – 12 mothers and 4 fathers of 12 infants were included Semi-structured interviews were used for qualitative data collection. The interview guide was developed based on the Middle Range Transition Theory.	<ul style="list-style-type: none"> <li>Parents experienced heightened anxiety and depression before hospital discharge, influenced by fear, uncertainty, and traumatic experiences. While emotional well-being improved over time, some parents continued to face lingering effects of guilt, self-blame, and vivid memories of the intensive care period.</li> <li>Parents faced challenges meeting their own physiological needs (e.g., sleep, nutrition) during hospitalization but adapted routines post-discharge to balance their infant's care with household needs.</li> <li>Hospitalization and caregiving impacted family finances due to lost income, travel expenses, and increased household costs. Support from employers, benefits, and extended family were vital in alleviating financial burdens for some families, while others faced significant financial hardships.</li> </ul>	High
(Gramszlo et al., 2020) United States of America	<b>Objective</b> To examine parental preference for intervention programs to support psychosocial needs.	Mixed methods study. Qualitative data analyzed using an inductive thematic approach. Sample – 20 mothers and 14 fathers of 21 young children with a congenital heart defect (CHD) Semi-structured interviews used for qualitative data collection. Parents also reviewed and commented on 3 psychosocial programs.	<ul style="list-style-type: none"> <li>Program Goals: Focused on empowering parents through education, self-care guidance, and effective communication, preparing them for post-hospital challenges and supporting their child's neurodevelopment while fostering social support.</li> <li>Program Structure: Delivered through formalized, stage-specific support with brief, personalized interventions in small groups or one-on-one settings, integrating multidisciplinary teams and peer mentorship.</li> </ul>	High
(Nayeri et al., 2021) Iran	<b>Objective</b> To explore the meaning of parenting a child with CHD	Qualitative explorative study using content analysis approach and constant comparative analysis. Sample – 17 parents Semi-structured interviews were used for data collection.	<ul style="list-style-type: none"> <li>Parenting a Child with CHD: Involved emotional breakdowns characterized by denial, guilt, sadness, and isolation, compounded by the catastrophic burden of care, including financial hardship, social restrictions, and distress over medical procedures.</li> <li>Coping and Challenges: Parents turned to spirituality for comfort and meaning, viewing their child's condition as a divine test, while also navigating significant marital, emotional, and psychological strain due to external pressures like poverty and difficult living conditions.</li> </ul>	Moderate
(Ni et al., 2019) China	<b>Objective</b> To explore the home care experiences of those taking care of children diagnosed with a CHD.	A qualitative design Sample – 17 mothers, 5 fathers Semi-structured, open-ended interviews were used for data collection. Data on caregiver experiences were collected both prior to and after cardiac surgery.	<ul style="list-style-type: none"> <li>5 main themes were generated from 12 themes: excessive mental burden, under pressure and agony, the impact on personal life, adapting roles constantly, and self-fulfillment in caring activities.</li> <li>Parents were fearful that they would not provide adequate care to their child and often put blame on themselves for their child's defect.</li> <li>Healthcare workers can identify the needs of caregivers and help them feel better supported from diagnosis to after surgery.</li> <li>Health care workers can alleviate some stress, anxiety, guilt, and hopelessness experienced by caregivers by providing education and psychosocial support.</li> </ul>	High

Authors, year of publication, origin/country of study	Research Question or Objective (Phenomena and Population)	Qualitative Methodology	Major Findings	Quality Appraisal JBI
(Thomi et al., 2019) Switzerland	<b>Objective</b> To explore both mothers' and fathers' experiences from prenatal or postnatal diagnosis of their newborn's congenital heart disease (CHD) to the first discharge after heart surgery.	A qualitative research approach using a constructivist paradigm and Braun and Clarke's thematic analysis was used. Sample – 18 parents Semi-structured interviews containing open-ended questions developed based on literature and the authors' experiences in the field.	<ul style="list-style-type: none"> <li>• Overarching theme was that parents experienced demanding emotional and hands-on challenges, feeling as though they were on a roller-coaster from diagnosis to hospital discharge.</li> <li>• Key Experiences: Parents faced shock and fear during diagnosis and delivery, stress and mixed emotions in the pediatric intensive care unit and surgery, and initial anxiety followed by gradual adaptation on the pediatric cardiac unit. Discharge evoked both readiness and lingering concerns.</li> <li>• Parent-HCP Interplay: Trust was built through transparency, continuity, and compassionate care. Parents valued clear communication and empathy but were distressed by excessive information or errors. Multidisciplinary support was essential for navigating the journey.</li> </ul>	High
(Vainberg et al., 2019) Israel	<b>Objective</b> To explore the experiences of parents as primary caregivers for their child in the intensive care unit with a CHD. Establish a greater understanding of personal feelings in relation to experiences with the medical system.	Interpretative phenomenological analysis and grounded theory. Sample – 12 Parents Semi-structured interviews were used for data collection.	<ul style="list-style-type: none"> <li>• Parent-infant bonding and attachment were disrupted as parents felt their role was altered.</li> <li>• A lack of perceived social support negatively impacted parents as it was associated with feelings of isolation and loneliness.</li> <li>• Parent's emotional distress increased when they felt medical staff were insensitive to their emotions and beliefs.</li> <li>• Parents felt relief and support when the medical staff acknowledged their needs opposed to just viewing them as associated with their child.</li> </ul>	High
(Wei et al., 2016) United States of America	<b>Objective</b> To describe parents' experiences when their child with CHD underwent heart surgery. Took place in a children's hospital on the east coast in the US. Recruitment was on the cardiac unit between July–Dec. 2014	Descriptive Phenomenology. Authors stated they combined the data analysis methods of Colaizzi, Giorgi, Swanson-Kauffman and Schonwald, Wojnar and Swanson, and Wojnar, Swanson, and Adolfsson. Sample – 13 Parents In-depth interviews conducted for data collection.	<ul style="list-style-type: none"> <li>• Parents experienced intense emotional responses, including shock, heartbreak, and self-blame, upon learning of their child's heart defect, regardless of timing or type of diagnosis.</li> <li>• Fathers expressed concern for both their child and their wife, while mothers struggled with making surgical decisions.</li> <li>• Parents found relief from their anxiety when connecting with others who shared similar experiences.</li> </ul>	High

## Results

The analysis of reported interview quotes in qualitative studies allowed for the identification of several experiences that illustrate the informational, emotional, and practical supportive care needs of parents with infants diagnosed with a CHD at birth, including those hospitalized for treatment. Each category reflects a distinct type of support parents required during their hospital experience, which was often unmet or partially fulfilled.

### Informational Support Needs

Parents frequently expressed a need for more comprehensive information about their child's diagnosis, treatment, and care processes. Many felt confused or overwhelmed by medical terminology, which led to feelings of disempowerment and frustration. Key quotes demonstrating the informational support needs included: *"We were upset that we didn't understand my son's illness"* (Nayeri et al., 2021), emphasizing that parents lacked a clear understanding of the diagnosis and needed support to process complex information. Informational support related to the causal factors and formation of the defect were also reported, *"I've got time to myself to be constantly thinking about what did I do wrong, what did I do wrong in my pregnancy"* (Gaskin et al., 2021), demonstrating the need for the delivery of accurate information to address parental guilt and misconceptions. *"We would've felt more empowered if we could have known things from the beginning and been physically caring for her more"* (Gramszlo et al., 2020), highlighting that early access to information could have made them feel more involved in their child's care. Similarly, *"I tried to cope by learning everything I could about his diagnosis. I asked endless questions, I read journal articles, I memorized what drugs he was on and what they all did. This helped to at least make me feel like I was a small part of the team keeping this sweet baby alive"* (Gramszlo et al., 2020), illustrating how learning about their infant's condition became a coping mechanism and fostered a sense of involvement. *"We didn't know what these words were, what this defect in the baby even was and where it had come to us from"* (Vainberg et al., 2019), further showing the importance of clear communication in helping parents comprehend their infant's condition. Collectively, these quotes from multiple studies demonstrate the need for clear information regarding their infant's diagnosis and care needs to fulfill their informational support needs.

### The Benefits of Informational Support

The positive impact of providing information to parents in a way they understand was demonstrated by one parent who said, *"They really explain everything... it really gives you a sense of control and understanding"* (Vainberg et al., 2019). Thus, healthcare providers thoroughly explaining medical information may fulfill the informational support needs of parents. Additionally, parents valued opportunities to ask questions and observe procedures, over reviewing printed resources, as seen in *"We observed how [and] to what they [the*

*nurses] reacted. We learned to like this, rather than buy any leaflets"* (Thomi et al., 2019). Direct interactions with healthcare professionals, as one parent described, were valuable: *"We were encouraged to ask questions, we were informed very well by different people, by nurses and physicians. We were involved and taken seriously"* (Thomi et al., 2019).

### Emotional Support Needs

The emotional journey of having an infant hospitalized with CHD was filled with anxiety, isolation, and a deep need for empathy from healthcare providers and peers. Parents expressed a strong desire for emotional support from people who understood their experience and could provide validation and compassion. Key quotes demonstrating the emotional support needs included: *"I've cried a lot, I've looked at other people... I feel like crying now"* (Gaskin et al., 2021), demonstrating the vulnerability experienced by parents, highlighting their need for empathetic support during the challenging journey of navigating their infant's diagnosis and treatment. *"I'm going to the house of those who have this problem. I ask what you did"* (Nayeri et al., 2021), shows that peer support from others who had been through similar situations was emotionally reassuring. While statements such as, *"There was a lactation specialist who was insisting that I get back to breastfeeding and ignoring my stress over potentially hurting my baby... She was a knowledgeable professional but she wasn't very supportive. Pumping was what worked for us and she could have been more respectful and encouraging of our choice"* (Gramszlo et al., 2020), highlighting the importance of flexibility and respect for parents' decisions. Parents commonly experienced feelings of unpreparedness, uncertainty, and confusion that was heightened by caring for an infant with complex needs related to their CHD. *"I also wish someone would have told me that anxiety and PTSD are common for heart parents and that it is completely normal to feel overwhelmed, worried, scared, helpless, and isolated. I don't think I was prepared for all of those feelings and I certainly didn't know what to do with them"* (Gramszlo et al., 2020), identifying the need for emotional support to normalize parents' experiences of anxiety and trauma. *"During that month when he was hospitalized, there was no one for me to speak to"* (Vainberg et al., 2019), indicating a need for someone, such as a nurse, to be available for emotional support when caring for the infant. Additionally, parental responses of, *"Compassion. I was missing compassion from some [HCPs]"* (Thomi et al., 2019), demonstrating the emotional need for empathy from care providers. Collectively, these quotes from multiple studies demonstrate the need for empathetic support from nurses and other care staff to fulfill their emotional needs when vulnerable.

### The Benefits of Emotional Support

One parent expressed appreciation for the emotional support provided in the hospital by saying, *"It was nice to have their guidance but not be forced to do things their way so I could*



learn to parent and bond with my baby in an almost normal way, despite being inpatient" (Gramszlo et al., 2020). This quote illustrates how guidance and a holistic approach allowed parents to bond with their infants in a way that was natural and gave them some control. Parental presence and compassion from healthcare providers were also significant in terms of emotional support. One parent emphasized the importance of time spent on the unit stating, "I was able to spend a lot of time here [on the unit]. And that takes away the fear" (Thomi et al., 2019). Additionally, the value of peer support was also noted as a source of comfort as a parent shared, "I could not calm down while I was waiting, until I talked to other people who had some similar experiences. That was really helpful" (Wei et al., 2019). Therefore, these quotes reveal how time, empathy, and peer relations can help parents emotionally.

### Practical Support Needs

Parents needed practical support in managing day-to-day responsibilities and self-care during their child's hospitalization. They reported often feeling overwhelmed by the demands of being constantly present in the hospital and maintaining responsibilities outside the hospital. Key quotes demonstrating the practical support needs included: "When he needed surgery, we were in hospital for over one month with my child alone. I hoped to have one hour to take a rest somewhere" (Nayeri et al., 2021), demonstrating the need for time to rest and recover while remaining in the hospital. Self-care needs were also apparent, "I was just really feeling really poorly myself... but in that situation you kind of think, no... forget me, your baby's like... severely poorly" (Gaskin et al., 2021), emphasizing the need for support that addresses parents' own well-being, as their instinct to prioritize their infant's needs often leads to neglect of their health. "I wish they had considered how involved we wanted to be, especially in the ICU... They could have asked us what we wanted to do or if there was anything we weren't comfortable doing" (Gramszlo et al., 2020), pointing to the desire for involvement in care while balancing the need for a "normal" experience. Anticipatory toll of caregiving was also expressed. "Originally, I planned to pursue postgraduate studies in 2 years and look for new career development opportunities, but the child is not well and I don't have time and energy to learn" (Ni et al., 2019), illustrating the sacrifices parents made due to the demands of care. "In order to take care of the sick child, I never participate in my company's dinners and activities, let alone travel" (Ni et al., 2019), showing how the burden of caregiving responsibilities limited other life activities. "I have to take care of my child all the time, so I have no time to do housework... I have no work now and our family life depends on my husband. His salary is only US \$2000 per month, and I am almost unable to pay the medical fees" (Ni et al., 2019), reflecting the financial burdens and lack of time for employment, let alone household tasks. "I wanted to hold my baby and comfort him. But I can't do it... The beeping sounds of the machines freaked me out"

(Wei et al., 2016), highlighting how parents experienced challenges in providing comfort to their infants due to the hospital environment. Collectively, these quotes from multiple studies demonstrate the need for support with caring for their infant, as well as themselves, to fulfill their practical supportive care needs.

### The Benefits of Practical Support

Parents appreciated the gentle reminders from healthcare providers to practice self-care while caring for their child. One parent shared, "They even had recommendations, like go and eat, drink, take care of yourself... I think that's what encouraged me was that they understood that I needed to preserve my strength" (Vainberg et al., 2019). This encouragement offered support for addressing the practical needs of the parent, such as eating and sleeping, reinforcing the importance of self-care to sustain their strength during challenging times.

## Discussion

The findings from this synthesis of literature highlights the diverse and complex supportive care needs of parents with infants hospitalized for CHDs. To our knowledge, this study is unique in its use of social support theory, providing an important perspective to inform nursing practice. The codebook thematic analysis conducted revealed that parents face significant informational, emotional, and practical challenges, aligning with themes identified in previous literature on parental anxiety, when their infant is undergoing surgery for a CHD (Kumar et al., 2019; Simeone et al., 2017). Therefore, it is evident that informational, emotional, and practical support all play a role in empowering parents, reducing distress, and enabling them to participate actively in their child's care.

### Informational Support: Empowerment Through Knowledge

The need for clear, comprehensive information about their child's diagnosis, treatment options, and care processes was a recurring theme, demonstrating parents' desire to feel competent and involved (Gaskin et al., 2021; Gramszlo et al., 2020; Nayeri et al., 2019; Vainberg et al., 2019). Previous studies have similarly identified that a lack of knowledge can exacerbate parental anxiety, stress, and a sense of helplessness when dealing with a CHD diagnosis (Azhar et al., 2018; Kumar et al., 2019; Simeone et al., 2017). Information, especially when presented with empathy and in lay terms, can empower parents, enhance their understanding, and enable them to engage in informed decision-making (Azhar et al., 2018; Tallon et al., 2015).

For nursing practice, this reinforces the importance of providing structured, individualized education that is responsive to parental questions and paced according to their emotional readiness (Machado Amazonas et al., 2023; Wilandika et al., 2023). Additionally, practical teaching methods, such as demonstrations and allowing for questions from parents,

could help parents retain complex information better than informational leaflets alone (Simeone et al., 2017; Thomi et al., 2019). Future interventions might also incorporate multimedia tools, such as videos or interactive platforms, to make information accessible and adaptable to diverse learning preferences.

### **Emotional Support: Validating and Normalizing Parental Experiences**

The emotional journey of parents in this study revealed intense feelings of anxiety, isolation, and the need for validation, aligning with the emotional support needs documented in other studies on parental experiences of having an infant with a CHD (Simeone et al., 2017; Thomi et al., 2019; Wei et al., 2016). Parents expressed a desire for compassion and understanding from healthcare providers, as well as opportunities for peer support, which could normalize and alleviate their emotional struggles (Thomi et al., 2019). Similar findings of distress, uncertainty, and fear have been reported in a qualitative meta-synthesis of parental experiences when their child is diagnosed with a CHD (Dandy et al., 2024). Having a trusted healthcare provider to confide in, along with accessible peer support, could reduce feelings of isolation and promote positive coping skills.

Nursing practice implications emphasize the importance of incorporating emotional support into routine care for parents of infants with CHDs. One strategy is the integration of compassionate communication and empathy-focused care into nursing training. Nurses should be trained to recognize and respond to the emotional needs of parents, providing reassurance, active listening, and empathy throughout their interactions (Fuglsang et al., 2023). This approach helps alleviate parental anxiety, creating a more supportive environment for both the parents and their child. Additionally, nurses can play a pivotal role in facilitating peer-support programs or group sessions within the hospital setting. These opportunities allow parents to connect with others who are going through similar experiences, providing a sense of shared understanding and emotional relief.

### **Practical Support: Balancing Hospital and Home Demands**

Practical support needs highlighted the struggle of balancing hospital commitments with other life responsibilities, such as employment, finances, and self-care (Gaskin et al., 2021; Ni et al., 2019). Parents often find themselves caught between being present for their child in the hospital and fulfilling other obligations at home or work, creating a sense of guilt (Ni et al., 2019). These challenges extend beyond just the basics of care, as they encompass the emotional burden of not being able to fully attend to all their roles, even when transitioning to caring for their infant at home (Gaskin et al., 2021; Vainberg et al., 2019). These findings demonstrate the need for support in areas such as ways to care for their child and themselves simultaneously.

For nursing practice, this emphasizes the promotion of self-care by proactively assessing and addressing parents' physical and practical needs, emphasizing the importance of rest and nutrition to enhance the parents' overall well-being. Practical measures, such as offering the family a reclining chair for bedside rest and creating relaxing spaces within the hospital, can support parents' well-being and improve their ability to care for their child, because they feel less stressed. Additionally, nurses can empower parents by providing clear guidelines on participation in care and creating opportunities for bonding while navigating the ICU environment. This can include providing step-by-step instructions on how they can provide their child with skin-to-skin contact to facilitate bonding and support their child's recovery.

### **Limitations**

The search of databases was limited to the past 10 years to capture more recent experiences. However, this may have omitted experiences before this time frame. Additionally, interest was specific to diagnosis during the neonatal period, which may have resulted in exclusion of parental experiences captured at other times.

### **Future Directions for Research**

This narrative synthesis provides a foundation for future research aimed at gaining deeper insight into the specific informational, emotional, and practical supportive care needs of parents with infants diagnosed with CHDs at birth in hospital. Given that a lack of information was identified as a theme in the data, future research could explore a co-design approach, collaborating directly with parents to develop informational resources that are specifically tailored to their unique needs. By directly asking parents about their needs, future studies can identify specific gaps and opportunities for improvement in the care provided to these families. Addressing these gaps will allow for future studies to contribute to the design of holistic, evidence-based practices that promote family-centred care.

### **Conclusion**

In conclusion, the effects of CHDs extend beyond the infant, impacting not only the health of the child but also the emotional well-being, family dynamics, and daily lives of their parents. The diagnosis of a CHD presents a unique set of challenges for families, particularly in the form of heightened stress, disrupted family roles, and the overwhelming need for clear, compassionate guidance. This narrative synthesis, generated from a secondary analysis of qualitative literature, highlights that parents require comprehensive informational, emotional, and practical support to navigate these challenges effectively. Recognizing these needs, healthcare providers, especially nurses, play a critical role in delivering support that is both informative and empathetic, facilitating family involvement and alleviating parental anxiety. Therefore, addressing these needs not only improves the

immediate hospital experience for parents, but also leads to better health outcomes for the child, ultimately enhancing family well-being.

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