Review
Canadian Women’s Heart Health Alliance

The Canadian Women’s Heart Health Alliance Atlas on the Epidemiology, Diagnosis, and Management of Cardiovascular Disease in Women—Chapter 3: Patient Perspectives

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ABSTRACT
In recent years, public awareness campaigns have targeted knowledge gaps and inequities in care while focusing on the unique female experience and heightened cardiovascular disease (CVD) risk profile. Recognizing and understanding the sex and gender constructs, barriers, facilitators, and factors that affect access, treatment, and recovery after an acute cardiac event from the unique patient perspective is a key step in transforming clinical practice and care patterns. The aim of this atlas chapter is to provide a knowledge review and to identify gaps regarding the experience of living with CVD from the perspective of the female survivor. The sections are as follows: (1) experiencing and living with CVD as a woman; (2) stopped at the

RESUMÉ
Depuis quelques années, des campagnes de sensibilisation du public ciblent les lacunes dans les connaissances et les iniquités en matière de soins, notamment l’expérience unique que vivent les femmes et leur profil de risque de maladie cardiovasculaire (MCV) accru. Pour transformer la pratique clinique et les modèles de soins, il est crucial de reconnaître et de comprendre les conceptions relatives au sexe et au genre, les obstacles, les éléments facilitateurs ainsi que les facteurs qui influent sur l’accès aux soins, le traitement et le rétablissement après une manifestation cardiaque aiguë, du point de vue unique des patientes. Ce nouveau chapitre de l’atlas dresse un bilan des connaissances et cerne les lacunes quant à l’expérience des

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Recognizing and understanding the sex and gender constructs, barriers, facilitators, and factors that affect access, treatment, and recovery after an acute cardiac event from the unique patient perspective is a key step in transforming clinical practice and care patterns. The aim of this atlas chapter is to provide a knowledge review and to identify gaps regarding the experience of living with CVD from the perspective of the female survivor. The sections are as follows: (1) experiencing and living with CVD as a woman; (2) “stopped at the gate”: barriers to accessing acute cardiovascular care; and (3) action items to “open the gate” to women: what our patients want and need. The final section culminates with targeted recommendations stemming from recent literature and most importantly, from women living with the experience of CVD. The key messages of this chapter are summarized in Figure 1.

**Experiencing and Living With CVD as a Woman**

"Women patients share with us that the aftermath of a CVD event is both daunting and stressful and constitutes a complete life change. Even after years of living with heart disease, concern regarding the risk of having a recurrent event is always present."

—H. Sarfi, Women@Heart program participant, Personal communication, June 28, 2020

Studies have shown that patients with CVD rate their health and quality of life at a lower level than the average population. In particular, women experience a lower degree of perceived health. During the initial recovery phase after CVD diagnosis, women are in need of health care support, but often these necessary supports are not available and the resultant anxiety, fear, insecurity, and lack of closeness can increase feelings of vulnerability. Women report more intense post-traumatic stress disorder symptoms after MI with less improvement in symptoms over time, compared with men. Indeed there are limited data, and much of what is known about women living with CVD or recovering from an acute cardiac episode is reflective only of the first 12 months after an event, thus highlighting the need for research into recovery and adjustment beyond this time period. Women experience higher levels of anxiety, depression, perceived stress, and lower health-related quality of life than men in the first year after an MI, all factors indicative of psychological issues extending beyond the acute phase of recovery. Limited data suggest that even 5 years after MI, women continue to describe ongoing fear and anxiety about the future and difficulty with moving forward in recovery, and experience panic attacks about the
The possibility of MI recurrence. Not surprisingly, it has long been documented that women have greater mortality in the year after an MI and are more likely to have poorer outcomes compared with men.

Women might be disproportionately affected in their partner relationships after a CVD diagnosis resulting in conflicts and/or changes from preillness equilibrium; this might be manifested through overprotection by the non-affected partner, resulting in communication difficulties or major domestic role issues. Although American and European guidelines for resuming sexual activity after cardiac diagnoses exist, only 12%-35% of women receive counselling on when or how to safely resume sexual activity. Women without counselling are more likely to delay intimacy. Fear, anxiety, depression, or ignorance can affect a woman’s resumption of former sexual activity. However, by 1 year post diagnosis, Lindau et al. reported that 90% of previously sexually active women had resumed sexual activity.

Consequently, more women than men (42% vs 30%) with no baseline intimacy problems experienced at least 1 sexual functioning difficulty after MI, most commonly, vaginal dryness and decreased libido. Overall, female sexual dysfunction has been noted in 60% of women with coronary artery disease (15%-65%), compared with 33% of age-matched healthy women without coronary artery disease (15%-43% worldwide).

Social support in the form of relationships with family and friends, as well as peer support from other women with CVD, has been identified as an integral component in the recovery process for women after a cardiac event. Social relationships and environments can directly influence recovery trajectories in positive and negative ways. Family support can provide strength and comfort; however, some women identify that a lack of family support can have negative consequences on recovery. Social roles within the family can take precedence over personal recovery needs and expectations might be perceived as stressful, limiting the ability to concentrate on functional health and recovery.

Even with the support of family and friends, women might continue to experience challenges and psychosocial stress requiring a reframing of their health needs. Indeed, these circumstances often can only be understood by those who share the lived experience of acute CVD and recovery. Thus, peer to peer support and counselling groups have evolved and are recognized as important and meaningful tools in enabling effective recovery in women with a CVD diagnosis. Preliminary data from University of Ottawa Heart Institute, Toronto Rehabilitation, and Women’s College peer support initiatives in the respective cardiovascular prevention and rehabilitation programs have rendered promising results, which further emphasize the importance of providing opportunities for women to share...
their lived experiences with each other during recovery and thereafter.  

“Stopped at the Gate”: Barriers to Accessing Acute Cardiovascular Care

Women have described a serious barrier to access for acute cardiovascular care, or being “stopped at the gate”—generally referring to the emergency department (ED), when presenting with symptoms that might differ from those traditionally associated with acute coronary syndromes (ACS) as observed in the male experience. Shockingly, the Heart and Stroke Foundation of Canada Ms. Understood Report shared that early heart attack symptoms were missed in 53% of all women seen in the ED.  

Women might present with fewer classic symptoms of chest pain (31% compared with 42% for men), especially younger women.  Women’s symptom descriptions often include fatigue, dyspnea, weakness, arm, back or jaw pain, palpitations, light-headedness, nausea, or loss of appetite. However, a more recent single-centre study of primarily Caucasian women who presented to a European ED showed that women, even more than men, described what were defined as “typical” chest pain symptoms, infringing that classic symptom description might be interpreted differently when expressed by a woman.  

This lack of diagnosis and/or misdiagnosis has been attributed to multifactorial sex-specific issues including variation in symptom profile from the “typical” male symptom description of retrosternal crushing chest pain, gender-nuanced language, and communication (women might not say the words “chest pain,” as men most often do, but instead describe chest pressure or tightness). Furthermore, traditional approaches to risk stratification can result in the under-recognition of sex-specific presentation, misdiagnosis, and delayed recognition of ACS.   

Data recently extracted from a closed Facebook group (n = 19; mean age, 44.7 years), known as “Canadian Women with Medical Heart Issues,” summarized the experience of women subsequently diagnosed with cardiac disease, but who were dismissed with the following diagnoses upon initial presentation to the ED: (1) anxiety; (2) pneumonia; (3) perimenopausal symptoms; (4) drug abuse (specifically cocaine); (5) inadequate food intake; (6) obesity; (7) vaginal prolapse; and (8) fabrication of symptoms. This immediate lack of suspicion for a diagnosis of ACS in women results in a domino effect, in which less than one-third of women experiencing a heart attack receive standard care within time frames as mandated in best practice guidelines. Specifically, review of available North American data indicated that only 29% of women received an electrocardiogram within the benchmark 10 minutes for ACS diagnosis, compared with 38% of men, and in cases in which a thrombolytic therapy was indicated, only 32% of women received this therapy within the benchmark 30 minutes, compared with 59% of men.  

Similar findings have been reported in the global literature. In a Japanese study, during follow-up, women were less likely to be treated with a rhythm control strategy than their male counterparts, including catheter ablation of atrial fibrillation.  

Clearly, there is a need for education and an increased awareness of sex-unique presentations of CVD, acutely in the ED, and during recovery and follow-up. These sex-specific differences must be heard, understood, and properly addressed through broadening education and information available to health professionals and the public.   

Action Items to “Open the Gate” to Women: What Our Patients Want and Need

There is a critical need for sex- and gender-specific strategies to be implemented to improve cardiovascular outcomes for women. These opportunities to improve survival rates and reduce recurrence rates for women require defined procedural changes at all levels within the health care system.   

Primary care and ED environments

1. When women present with symptoms for which acute cardiovascular events are within the differential diagnosis, introduce specific procedural changes and checklists to ensure that higher-risk possibilities are ruled out before assessing for lower-risk conditions. This will serve to recognize and address unconscious bias, which results in assumptions of lower-risk conditions, and improve survival and recovery for women. This approach has been shown to have significant positive effect.  

2. Establish sex- and gender-specific clinical diagnostic protocols for patients who present to the ED or family physicians that address known differences in risk factors and possible variations in symptomatology.  

3. Require ED physicians/trainees to be regularly retrained on emerging cardiac research that affects diagnosis and care specific to sex and gender differences and to collaborate with specialists (cardiologists) to order tests/diagnostics that are generally only ordered after seeing a cardiologist.  

4. Revise laboratory testing protocols and “thresholds” (ie, high-sensitivity troponin level) to ensure sex-based result variances are considered; an ongoing prospective outcomes trial is evaluating this in Canada.  

5. After a CVD diagnosis has been established, reinforce and support referral to and enrollment in comprehensive cardiac rehabilitation as a priority in standard treatment plans for women, inclusive of psychosocial and lifestyle components. Affirm the recognition and understanding that there is a direct connection between the heart and the mind, for all cardiac patients, but especially for women. Women have expressed a desire for “women only” cardiovascular rehabilitation programs, and many centres have developed these in response. Many women face unique barriers to attendance at cardiovascular rehabilitation programs because of competing caregiving, transportation, and/or work-related responsibilities. Be sensitive to the individual woman patient’s desires, requests, and challenges, and as much as possible, tailor recommendations and provide assistance.  

6. Primary care and ED physicians should be aware of resources that are available in the community to their patients and be prepared to offer resources and contact information.
Institutional environments
1. Include rehabilitation and support programs in care pathways to enhance successful recovery and ongoing long-term health.
2. Order comprehensive, holistic prevention and wellness programs, which address the traditional physical cardiac rehabilitation, as well as a variety of other lifestyle adjustment and psychosocial support. Research shows that focused educational programs in a caring environment supporting women’s emotional health (such as the Women@Heart program, www.womenatheart.ca, developed by the Canadian Women’s Heart Health Centre, University of Ottawa Heart Institution; and, the “Women with Heart” peer support at Toronto Rehab/University Health Network’s Cardiovascular Prevention and Rehabilitation Program, www.uhn.ca/TorontoRehab/Clinics/CRSP_ Program), improves attendance at the cardiac rehab program; patient understanding of and accountability for their health; patient confidence in advocating for themselves; and, overall quality of life.
3. Create cultures that support open discussion with and respect for patients’ perspectives, and support an open and collaborative workplace. Provide training to improve listening and understanding skills to help clinical staff relate and make their patients feel comfortable.
4. Require mandatory training for all health care professionals on sex- and gender-based differences to improve cardiovascular outcomes for women.

Educational environments
1. Incorporate sex- and gender-based differences in core medical education curriculum and document proficiency in recognition, understanding, and implementation into diagnostic algorithms and care practices.
2. Implement and maintain continuing medical education for all health care professionals on sex- and gender-based differences in acute CVD diagnosis and care, as well as rehabilitation and recovery.
3. Integrate behavioural competency training into medical and allied health professional (nursing, physiotherapy, social work, dieticians) education with required milestone achievement and maintenance of certification.

Research environments
1. Standardize documentation and reporting of sex- and gender-disaggregated data in studies of CVD.
2. Ensure sex- and gender-specific analyses are completed and that there is equal representation of women in all clinical trials (or justification as to why not possible or applicable).
3. Use appropriate study designs and tools to detect sex and gender effects.

Policy environments
1. Increase government support targeting more cardiovascular research in women.
2. Increase awareness of CVD risk that portrays the diversity of at-risk women from all ethnicities, races, and ages and those who identify with various gender identities, expressions, and social roles through public health education/ mass media.
3. Integrate targeted risk factor awareness specific to women of childbearing age and nontraditional risk factors (gestational diabetes, preeclampsia, postpartum depression, low birth weight infants, etc)—a pivotal point early in life to make sustainable changes for long-term health and well-being.

What patients can do
Participate more fully in one’s care and recovery by:
1. Attending recommended programming (cardiac education, cardiac rehabilitation, peer support, etc).
2. Becoming a research participant to support new learning and improvements in treatments and program design.
3. Joining research studies as patient partners/investigators—be curious; ask questions that you believe are important for clinicians and researchers to consider in their research methods, approach, analysis, and interpretation.
4. Becoming more educated about one’s diagnosis and recovery—recognition of the signs and symptoms of heart disease, awareness, and understanding of one’s own risk profile.
5. Taking accountability for what is within one’s own control, listen to your body and advocate for your own health, asking questions, understanding the role of self-advocacy, and providing valuable feedback to health care providers.
6. Becoming an advocate for others by sharing your story and information on women’s heart disease, the lived experience and recovery, and/or leading a peer support group.

Conclusions
Over the past decade, significant strides have been made in the awareness of sex and gender differences in the diagnosis, treatment, management, and rehabilitation for women living with CVD. However, there is much work yet to be done.

It is imperative to hear the perspectives of women with lived experience of CVD to understand their journey, including ongoing challenges and unmet needs. The importance of valuing support from family, friends, and peers as well as having open dialogue with health care providers has been identified as key drivers promoting women’s recovery.

The recommendations outlined in this chapter provide further insight into women’s experiences after an acute cardiac event and highlight the need for continued diligence and advocacy, with implementation of sex- and gender-specific strategies as described to improve cardiovascular outcomes for women.

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