Commentary

Addressing the Bias in Cardiovascular Care: Missed & Delayed Diagnosis of Cardiovascular Disease in Women

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1. The Problem

In January 2021, at the Convening on Missed and Delayed Diagnosis of Heart Disease in Women, national experts and healthcare stakeholders heard the personal journeys shared by WomenHeart Champions – women living with heart disease. There was a distinct pattern in each story, years of “normal results”, being told “it is all in your head”, incorrect diagnoses of “asthma” or “anxiety”; all resulting in missed and delayed diagnoses of heart disease among women.

Cardiovascular disease (CVD) is the leading cause of mortality among women in the United States (US), resulting in more deaths than all forms of cancer combined.[1] Over the past 20 years, transdisciplinary research made advances to better understand CVD in women.[2] There is an increased awareness that conventional atherosclerotic CVD (ASCVD) risk factors, such as hypertension, tobacco use and diabetes mellitus, impact women differently than men.[2–4] Unique to women are also the female-specific and female-predominant risk enhancers that should be considered in the ASCVD risk assessment of women,[5] which have the ability to further refine the risk assessment based on biological sex.[6]

Despite these advances, the prevalence of traditional ASCVD risk factors including diabetes mellitus, obesity, and hypertension has increased among younger women than 55 years old over the past decade.[7,8] Additionally, the rate of decrease in CVD-related deaths has plateaued and unfortunately increased in younger women, with approximately one-third of CVD events among women less than 65 years old.[7,8] Despite almost two decades of national efforts to increase women’s awareness of heart disease as the leading cause of death, awareness has decreased from 65% in 2009 to 44% in 2019 among all women across race/ethnicities, and most notably among 25-64 year-olds.[9] Additionally, only 22% of primary care physicians and 42% of cardiologists felt adequately prepared to assess CVD risk in women.[10] This likely contributes to the noted underutilization of preventive therapies in women, when compared to men.[11,12]

Once women have CVD, there are continued sex disparities in their diagnosis, treatment, and management, resulting in worse outcomes for women. Such sex differences have been demonstrated across CVD diagnoses including acute coronary syndromes, heart failure, and valvular disease with delays in care.[13] Underutilization of guideline directed medical therapies and cardiac rehabilitation,[2] and less aggressive treatment,[14–16] when compared with men. As a result, we continue to see higher mortality rates and rehospitalizations in women, compared with men.[17] Additionally, women remain underrepresented in clinical cardiovascular trials, making it difficult to fully appreciate sex differences in novel medical therapies, devices, or other interventions.[18]

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1.1. Finding Solutions

To directly address these issues, WomenHeart: The National Coalition for Women with Heart Disease in partnership with the Society to Improve Diagnosis in Medicine (SIDM), was awarded funding from the Patient-Centered Outcomes Research Institute (PCORI) to host a convening of diverse stakeholders to specifically address missed and delayed diagnosis of heart disease in women. In preparation for the convening, a steering committee of WomenHeart and SIDM leadership, WomenHeart Champions (patient leaders), clinicians, and policy stakeholders met virtually throughout 2020. The objective of the steering committee was to conduct a rigorous environmental scan with compilation of the literature to identify research gaps in the diagnosis of cardiovascular disease in women. The steering committee identified gaps along the diagnosis spectrum defined by The National Academy of Medicine’s conceptual framework for diagnosis.[19] For these objectives, the selected CVD in women were heart failure, spontaneous coronary artery dissection [SCAD], hypertension, microvascular disease, valve disease, epicardial obstructive disease, and pregnancy-related cardiovascular disorders.

Due to the coronavirus disease 2019 (COVID-19) pandemic caused by the SARS-CoV-2 virus the Convening on Missed and Delayed Diagnosis of Heart Disease in Women occurred virtually on January 27, 2021.[20] The convening engaged patients (WomenHeart Champions), primary care, emergency department and other specialty clinicians (including cardiologists, nurses, physician assistants), hospital leaders, healthcare advocates, policy makers, and experts from the Centers for Disease Control and Prevention and the National Institutes of Health. Members of the steering committee presented findings from the environmental scan, delivered state-of-the-art-reviews, and led interactive discussions. The presentations highlighted important gaps in patient-centered research, implicit bias, deficiencies in medical and lay community knowledge, in addition to inertia in clinical implementation of US guidelines, and gaps in US medical training; each believed to be important contributors to delayed and missed diagnosis of CVD in women.

A summary of the environmental scan process and literature findings is available on-line.[20] The environmental scan was the blueprint to guide small group discussions during the convening to provide granular recommendations of patient-centered outcomes research, using comparative effectiveness research. The groups used the PICOITS framework (Patient Population, Intervention, Comparator, Outcome, Timing, Setting).[21] There were four areas addressed to improve diagnostic rates, treatment, and clinical outcomes for women with heart disease: i) provider education, ii) patient-provider communications, iii) social determinants of health and iv) pregnancy-related diagnostic challenges.

The participants of the convening highlighted patient, provider, and system-level barriers along the diagnostic journey for women with heart disease as summarized in the final report.[20] Some important factors are summarized in Table 1:

1.2. Action Steps

In response to the identified barriers, the convening progressed to the critical step of recommending feasible, comparative effectiveness research questions to develop tangible, sustainable interventions. Extensive details of the recommended research studies, including a review of potential feasibility are in the convening’s publication.[20] A brief summary is in Table 2.

1.3. Using the Blueprint

The environmental scan and convening provided the necessary foundation to take the next action steps to decrease adverse CVD events among women. Now is the time to reinvest in solutions and efforts to improve the awareness of CVD risk factors that affect women among the lay population and across primary care and specialty care within the medical community. Education goals should reach beyond traditional CVD risk factors, but also highlight pregnancy-related and other female-specific risk factors. The interventions identified during the convening[20] highlight the importance of multidisciplinary, multi-level, collaborations to improve clinical outcomes, to support more timely and accurate diagnosis of heart disease in women, and to further decrease CVD-related deaths. The urgency and feasibility of new interventions need to be addressed in the context of the COVID-19 pandemic, incorporating its additional longitudinal adverse effects on clinical care, clinical outcomes, and social determinants of health. While acknowledging current challenges and strains to health systems, there are actions that can be started today (also see Central Figure):

- It is time to destigmatize women presenting with shortness of breath, chest discomfort, or other potential CVD-related symptoms
- Support and empower women to advocate for their healthcare and be part of the solution. A patient resource (https://www.womenheart.org/wp-content/uploads/2021/08/Misdiagnosis_Patient-Resource_FINAL.pdf) was created as an accompaniment to the report, which encourages women living with heart disease to take their own actions in support of better outcomes for their peers.
- Recognize and consider the impact of social determinants of health throughout the diagnostic and treatment process
- Continue to educate every woman on their primary or secondary CVD risk factors
- Refer women to WomenHeart for educational resources and access to peer support through the WomenHeart Champions – women heart disease patient leaders: https://www.womenheart.org/.
- Encourage your hospital to provide gender-sensitive cardiac care. Consider joining WomenHeart’s National Hospital Alliance to collaborate with colleagues across disciplines (ex: obstetrics/gynecology, rheumatology) to address female-specific and female-predominant risk factors.
- Do the research – identify one or more of the patient-centered outcome research questions proposed in the convening report20 and help build an evidence-base of solutions that improve the diagnostic process for women
- Increase representation of women in clinical cardiovascular trials
- Use resources from the American Society of Preventive Cardiology for patient and clinical education: https://www.asponline.org/clinical-resources/provider-tools/infographics/
Table 1
Diagnostic Challenges for Women with Heart Disease

| Diagnostic Challenge | Provider Level | Health System Level |
|----------------------|----------------|---------------------|
| **Access**           | Limited preventive and chronic care tailored to women with CVD | Limited public health outreach to women about CVD; Limited provider availability |
|                      | Limited time and/or attention; Limited knowledge of symptoms among women with CVD | Medical training insufficiently addresses CVD presentation differences between women and men |
|                      | Clinical signs of CVD are misinterpreted (i.e., wheezing); Limited knowledge of cultural/religious background | Limited visit time; insufficient training and/or comfort regarding physical examinations in women |
| **History**          | Financial barriers to additional testing: “No news is good news” | Insufficient CVD evaluation for women; Lack of result communication |
|                      | Symptoms attributed to non-cardiac diagnosis (i.e., anxiety); Implicit bias based on patient’s sex, gender, age, race, ethnicity, appearance | Barriers transitioning within and across systems; prioritization of referrals |
| **Physical Examination** | Limited time (i.e., work, caregiver); Financial barriers; unclear why referral is needed | Limited CVD research in women for guideline recommendations |
|                      | Lack of communication/closing loop with specialist | Inability to track patients lost to follow-up; Geographic disparities in longitudinal medical access |
| **Clinical Testing** | Financial barriers to additional testing: “No news is good news” | Insufficient CVD evaluation for women; Lack of result communication |
|                      | Symptoms attributed to non-cardiac diagnosis (i.e., anxiety); Implicit bias based on patient’s sex, gender, age, race, ethnicity, appearance | Barriers transitioning within and across systems; prioritization of referrals |
| **Assessment**       | Misdiagnosed (e.g., anxiety); Lack of empowerment to request additional evaluation | Limited CVD research in women for guideline recommendations |
| **Specialist Referral** | Limited time (i.e., work, caregiver); Financial barriers; unclear why referral is needed | Inability to track patients lost to follow-up; Geographic disparities in longitudinal medical access |
| **Follow-up**        | Misunderstanding of CVD diagnosis; Feels abandoned | Limited staff, appointments, community resources |

Table 2
Summary of Potential Comparative Effectiveness Research Questions and Interventions in Women with CVD

| Research Question: Do women who self-assess heart rhythm, blood pressure or other biofeedback using wearable devices receive an earlier, accurate diagnosis of CVD than women who do not? | Research Question: Are obstetricians/gynecologists (OB/Gyn) who receive dedicated training about CVD in women more likely to make accurate and timely diagnoses of heart disease? | Research Question: Do women seen in health systems that use telehealth-enabled remote cardiology consultations during the diagnostic process more timely and accurate diagnosis of heart disease than women seen in health systems without this virtual capacity? |
| Research Question: Evaluate the role of wearable devices in CVD diagnosis and treatment among women. | Intervention: Provide focused education and training to OB/GYN about CVD. | Intervention: Initiate/expand telehealth cardiovascular consultation services. |
| Research Question: Are women who access information or support from other women with heart disease more likely to be accurately diagnosed with CVD compared to those who do not? | Research Question: Does including women with heart disease in simulation training programs improve the diagnostic accuracy of clinicians, compared to clinicians who do not receive such training? | Research Question: Do women seen in hospitals that require admission after repeated emergency department visits have more timely and accurate diagnosis of heart disease than those seen in hospitals without this policy? |
| Intervention: Provide support groups and/or patient advocates for women with CVD. | Intervention: Increase representation of women in clinical and procedural medical simulation education. | Intervention: Evaluate the role of dedicated CVD diagnostic pathways for women presenting to the emergency department. |

2. Summary

Cardiovascular disease is the leading cause of morbidity and mortality in women, with increasing prevalence of cardiovascular risk factors, and disturbing changes in trends of CVD-related death, especially among younger women. Collaborative efforts of WomenHeart: The National Coalition for Women with Heart Disease in partnership with the Society to Improve Diagnosis in Medicine, with funding from PCORI advanced our knowledge of patient, provider, medical training, and health system research gaps needed to decrease missed and delayed diagnoses of CVD in women. This collaboration highlighted important next steps for patient-centered comparative effectiveness research to directly address the defined gaps. Now is the time for us all to follow the blueprint.

Declaration of Competing Interest

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CRediT authorship contribution statement

Heather M. Johnson: Conceptualization, Visualization, Writing – original draft, Writing – review & editing. Celina E. Gorre: Writing – review & editing. Amy Friedrich-Karnik: Writing – review & editing. Martha Gulati: Writing – original draft, Visualization, Writing – review & editing.
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