



Training/Practice Contemporary Issues in Cardiology Practice

Patient Care Journey for Patients With Heart Valve Disease

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Heart valve disease (HVD) is a common, serious, but treatable disease that affects more than 1 million Canadians. Too many people with HVD are receiving potentially life-saving treatments too late owing to a combination of low awareness, deficiencies in detection, and delays in diagnosis and unequal access to care.¹ In response to these major gaps in care, Heart Valve Voice Canada, a patient advocacy organization—co-led by patient representatives, clinicians, and researchers—developed a report that describes what an optimal-care pathway should be for people living with HVD and provides a series of recommendations to improve the journey of these people.

The Canadian report on the HVD patient journey builds on the European report published by the Global Heart Hub in 2020 and was developed under the guidance of a multidisciplinary advisory council, whose members included cardiac patients with personal experience and health care professionals engaged in HVD care in Canada. Prioritizing the patient perspective is the common thread

throughout the production of this report. To our knowledge, this is the first report in Canada and North America that provides a comprehensive overview of the entire patient journey from awareness and first detection to diagnosis, follow-up, and treatment. The report provides guidance and a roadmap to decision makers and professional organizations on what they should do to reduce the burden of HVD in years to come (Fig. 1, Table 1, Supplemental Appendix S1).

The Burden of Heart Valve Disease in Canada

HVD is the third most frequent cardiovascular disease after hypertension and coronary artery disease in high-income countries. Although data on HVD in Canada are limited, it is estimated that approximately 1,100,000 Canadians (~3.5% of the population) have significant HVD. It is worrying that the burden appears to be increasing rapidly as Canada's population ages. Between 2007 and 2017, the number of hospitalizations for HVD increased by 68% in Canada.^{2,3} The rate of mortality in untreated severe, symptomatic aortic stenosis, the most common form of HVD, is between 25% and 50% per year, and timely treatment is needed to avoid the worst outcomes.⁴

Canada's health care system implies that every person with HVD is entitled to universal coverage and accessibility at every stage of the care journey. Unfortunately, many Canadians

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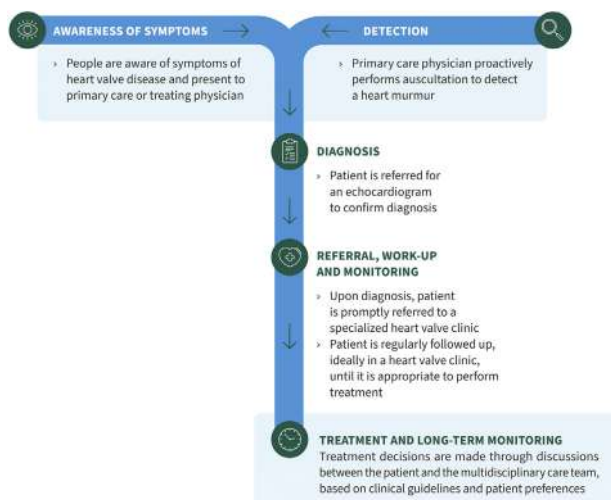


Figure 1. The ideal patient care journey for heart valve disease. HVD, heart valve disease

experience barriers to accessing primary care; fewer than one-half (43%) can get a same-day or next-day appointments when they are ill (Source: International profiles of health care systems 2020. New York: The Commonwealth Fund). Furthermore, inequalities in access persist and are often driven by the country's vast geography and urban—rural divide, potentially resulting in late diagnosis and inadequate monitoring and follow-up for people in rural communities. Access to health care, including specialist care, is often deficient in Indigenous communities. In addition, the causes, mechanisms, evolution, and symptoms of HVD differ substantially between women and men. As a result, HVD is underdetected, underdiagnosed, and thus undertreated to a greater extent in women.

Awareness

Despite its major burden, awareness of HVD remains low in the general population. Because of low awareness, there are often delays in the detection and diagnosis of HVD, and—as a consequence—these people may be treated too late in the course of the disease. Patient and professional cardiovascular organizations should develop national, provincial, and regional campaigns to raise public awareness of HVD (Table 1).

The symptoms of HVD may be difficult to recognize, as they vary among individuals and often mimic general signs of aging. Hence, building public awareness of the main symptoms of HVD is critical such that people experiencing any of these symptoms should see their primary care physicians without delay. Public funding should also be provided for patient organizations to ensure delivery of ongoing support and information to patients, families, and caregivers.

Detection in Primary care

Underdetection is a major issue in HVD. For example, a major UK study found that, among a cohort of 2500 people ≥ 65 years of age who were registered in primary care centres, 11.3% had moderate to severe HVD, but more than one-half

of these cases had not been previously diagnosed.⁵ In Canada, the inadequate access to primary care, which exists in many provinces, exacerbates this issue of underdetection of HVD.

Primary care practitioners and community partners should be alerted to the signs and symptoms of HVD and enter patients into appropriate care pathways. Every person older than 60 years of age or with pre-existing valve conditions should receive auscultation by stethoscope as part of routine annual check-ups (Fig. 1, Table 1). One way to improve detection of HVD at the primary care level may be to implement digital tools, including digital stethoscopes or electrocardiograms combined with artificial intelligence-based algorithms.

Diagnosis Via Echocardiogram

People with a heart murmur or with symptoms potentially related to HVD should be referred for specialist assessment and diagnosis, which ideally should be done in a dedicated clinic where available (Fig. 1).⁴ Echocardiograms should be performed by specialists with imaging expertise within 2 weeks of initial referral for symptomatic patients and within 6 weeks for asymptomatic patients (Table 1). It is important to ensure consistent quality of echocardiograms among different settings and that quality be monitored by relevant quality assurance programs. Reports from the echocardiography team to the referring primary care practitioner need to be consistent and provide clear, actionable steps to guide patient care. Additional tests, such as an exercise stress test, transesophageal echocardiography, computed tomography (CT), or cardiac catheterization may also be helpful to confirm the diagnosis.⁴

Referral, Work-up, and Monitoring

Every person diagnosed with HVD should be promptly referred for regular scheduled follow-up, ideally within a dedicated structure with the appropriate expertise (eg, heart valve clinic), including physical examination, echocardiogram, and discussion about the care plan within 4 weeks of initial diagnosis (Fig. 1, Table 1).⁴ Patients should be provided with a clear and centralized point of contact to report any changes in their conditions. During this monitoring phase of the patient journey, which may last several years, patient education is key to ensuring the clinical team is immediately made aware of any change to the patient's condition that may affect the need for a valve intervention.

Treatment and Long-term Follow-up

Timely referral for the appropriate treatment is crucial to ensure good outcomes.⁴ For example, delaying aortic valve intervention in low- and intermediate- surgical risk patients with symptomatic severe aortic stenosis by only 3 to 6 months may significantly reduce the survival rate. However, patients often experience delays in referral and do not receive effective interventions in time.¹ These delays have increased further with the COVID-19 pandemic. Specialist teams in heart valve clinics and multidisciplinary heart teams can help determine the correct timing and type of intervention.⁴ This ensures that treatment is delivered at a less severe stage of disease, thereby improving patient outcomes.

Table 1. Recommendations at key stages of the patient care journey

Stages of patient care	Recommendation	Targeted organization for recommendation implementation	Time goal for recommendation implementation
Awareness	1. Develop national and regional campaigns to raise public awareness of HVD	Patient and health care professional organizations	-
	2. Provide funding to patient organizations to ensure delivery of ongoing support and information to patients, families and caregivers	Federal and provincial governments	-
Detection in primary care	3. Ensure primary care practitioners are aware of the signs and symptoms of HVD and of contemporary treatment options	Patient and health care professional organizations	-
	4. Every Canadian over 60 should receive annual auscultation by stethoscope	Primary care practitioners	By 2025
	5. Integrate digital tools such as digital stethoscopes to aid in detection of HVD	Provincial government	-
Diagnosis via echocardiogram	6. Echocardiograms should be offered within 3 weeks of initial referral to symptomatic patients, and within 6 weeks to asymptomatic patients	Health care institutions and professional organizations	By 2025
	7. Increase the number of specialists able to perform quality echocardiograms, including in the community setting		-
	8. Implement quality assurance programs, and develop standardized templates for echocardiography reports to referring physicians		By 2030
Referral, work-up, and monitoring	9. Every person diagnosed with HVD should be promptly referred for regular follow-up, ideally within a dedicated structure (ie, heart valve clinic)	Health care institutions and professional organizations	-
	10. Provide to patients with HVD a clear and centralized point of contact to report any changes in their condition and receive their follow-up care		-
Treatment and long-term follow-up	11. Implement shared decision-making between the patient and multidisciplinary care team to select the most appropriate treatment for each individual	Health care institutions and professional organizations	By 2025
	12. Ensure that every Canadian with HVD has rapid access to innovative and evidence-based technologies	Federal and provincial governments	-
	13. Provide cardiac rehabilitation, including physical and psychological support, to all people with HVD	Health care institutions	By 2030
	14. Ensure that all patients have echocardiograms annually as part of their long-term monitoring	Provincial governments and professional organization	-

HVD, heart valve disease

Shared decision making between the patient and multidisciplinary care team is key to integrate patients' preferences and priorities and should be implemented systematically to improve outcomes and experiences (Fig. 1).⁴ Adoption of innovative interventions should be timely to ensure the best treatment options are available in Canada for people with HVD. Cardiac rehabilitation programs, including physical and psychological support, should be provided to all patients

with significant HVD both before and after intervention. Every patient should have echocardiograms annually as part of their long-term follow-up after intervention (Fig. 1).

We acknowledge that if all the actions that we recommend (Table 1) were implemented immediately, this would likely exceed the capacity of the health care system, which is currently limited and may not allow accommodating a large increase in HVD care volume. However, this report also

provides a strong argument and impetus for the augmentation and optimization of the health care system resources for the management of people living with HVD.

Conclusions

Addressing the gaps in the patient care journey is not important only for patients with HVD, it is also urgent if we want to protect the health and productivity of this growing population. Actions taken now will reduce the future burden of HVD on our society in terms of impaired quality of life, avoidable deaths, and costs to health care systems. To achieve this important goal, we call on decision makers across Canada to work closely with health care professionals, patient organizations, and the research community to ensure that all people with HVD have access to appropriate diagnosis and treatment without excessive delays (Fig. 1).

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Disclosures

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Supplementary Material

To access the supplementary material accompanying this article, visit the online version of the *Canadian Journal of Cardiology* at www.onlinecjc.ca and at <https://doi.org/10.1016/j.cjca.2022.02.025>.