



Editorial

The Need for Heart Failure Advocacy in Canada

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Heart failure (HF) is a leading and growing cause of cardiovascular morbidity, mortality, and health care use in Canada.¹ The disease is associated with marked impairment in both functional capacity and quality of life for patients and their caregivers.^{2,3} Despite the significant impact of this disease on the health of Canadians, there is limited awareness among health care providers, health care systems, governments, and patients and their families as to the magnitude of the HF epidemic, the natural history of the disease, and the potential benefits of available therapies.⁴

In the past decade, the Canadian Cardiovascular Society (CCS) Heart Failure Guidelines Committee and the CCS have developed outstanding clinical practice guidelines and knowledge translation tools to inform optimal care of patients with HF in Canada. Although HF advocacy remains outside the scope of the guidelines panel, it is a central mandate of the Canadian Heart Failure Society (CHFS). In this article, we outline some of the key challenges facing the advancement of patient-centred HF care in Canada and provide a call to action for all stakeholders, outlining key targets for health care system

redesign and policy initiatives that must be championed to affect meaningful change toward an optimal future for this disease state.

Impact of HF on Patients and Health System Outcomes

HF currently affects 600,000 Canadians and is a leading cause of hospitalization, which is a major driver of the \$2.8 billion dollars per year in direct health care costs spent on this disease.⁴ Despite major advances in diagnosis and treatment, Canadians hospitalized with HF have readmission rates in excess of 20% at 30 days and mortality rates upward of 30% at 1 year. These statistics have not improved over the past decade and are expected to rise as the population ages.¹

On admission to the hospital, patients with HF generally stay longer than others, have a higher frequency of comorbidity, and thus are overall greater consumers of health care services.⁵ Additionally, patient-reported outcomes including symptom severity, quality of life, and caregiver burden for individuals with HF are among the highest of any condition.^{2,6,7}

Building a System of Care for Patients With HF

Multiple studies and meta-analyses have shown that disease management interventions that focus on patient empowerment, education, careful clinical follow-up, and pharmacologic/device optimization are associated with decreased

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See page 1453 for disclosure information.

hospital admission and health care use as well as improved quality of life and survival.⁸ Furthermore, integration of primary and specialty care services in the management of these complex patients is associated with improved outcomes.⁹

In reality, however, the actual provision of HF care varies widely across the country and depends largely on the province and setting in which the patient resides (urban vs rural).^{10,11} Some regions of the country have invested in the development of specialized HF management programs, whereas others rely heavily on the available primary care infrastructure for providing the bulk of HF care.¹² The result is a disconnected patchwork of local systems, with resultant large inequities in access to appropriate HF care.¹³ These disparities in the delivery of quality services may be even more pronounced among geographically, culturally, and socially marginalized groups.^{14,15}

Even when HF services are available, the patient journey is frequently characterized by visits with multiple providers across multiple settings. As such, care is often undermined because transitions are not well defined or coordinated.

Although the CCS HF guidelines include best practices for multidisciplinary HF care and recommendations to support transitions across the care continuum, currently there is no organized and equitable system for HF management in Canada that spans the care continuum.¹⁰ Appropriate multidisciplinary management of and support for patients with HF in the community and other care settings is critical to ensuring improved outcomes for patients while lessening the burden of HF on the health care system.

Recommendation

Regional and provincial care pathways must be established in partnership between health authorities, specialists, and primary care groups that build on CCS HF guidelines and reflect local practice, including referral pathways and system capacity. In many instances, this may require resourcing and building new HF infrastructure to meet patient needs.

Quality Improvement With Quality Data: The Case for a National HF Registry

The provision of quality care must be a goal of any health care system designed to achieve optimal outcomes. Performance indicators, such as those developed by the CCS Quality Project,¹⁶ allow us to track our collective adherence to the delivery of quality HF care nationally; however, for this process to work, a data backbone must be present to enable measurement.

A plethora of data systems exist in Canada to describe inpatient outcomes and quality of care. In many jurisdictions, these efforts have expanded to include the use of live web-based HF dashboards designed to show performance metrics. Despite these advances in HF process of care measurement, several important deficiencies exist: (1) national data linkages are poorly developed and are not inclusive of all provincial jurisdictions; (2) there is a lack of both data granularity and key clinical data elements, especially left ventricular ejection fraction but also patient-reported outcome and experience measures; (3) data linkages between inpatient and outpatient medication use are still under development at many Canadian centres; (4) there is a nearly complete lack of

data regarding ambulatory HF treatment outside the multidisciplinary clinic environment, which is particularly relevant because > 90% of the experience of the patient with HF is in the generalist or primary care setting.^{17,18}

The yield for solving this problem could be large because the post-acute care discharge phase for HF is associated with a high risk of readmission and mortality. Data on transitions between clinical settings and health care providers will allow for the development of novel and more effective shared care strategies. Thus, a national HF registry would create the data platform for bringing together a collaborative team of stakeholders mandated to identify innovative solutions for closing HF care gaps through a continuous cycle of measurement and quality improvement. The result should be improved and cost-effective outcomes in alignment with the Institute of Health Improvement's Triple Aim.

Recommendation

A carefully constructed national HF registry designed to measure key HF care processes and adherence to guideline-directed care and to track patient- and system-level outcomes across the care continuum must be a priority for all those involved in the management of patients with HF.

Improved Outcomes Require Timely Access to Treatment

Over the past decade, the CCS HF guidelines have provided clinicians with up to date evidence-based treatment algorithms for the management of HF.⁸ Unfortunately, in some instances, HF therapies have not been made available to Canadians in a timely manner. For example, there was a 7-year delay between publication of the landmark Systolic Heart Failure Treatment With the *I_f* Inhibitor Ivabradine Trial (SHIFT) trial¹⁹ and Health Canada's approval of ivabradine for the treatment of HF. Meanwhile, this drug has been available in > 100 countries globally.

Further, even after receiving notice of compliance from Health Canada, access to lifesaving treatments is further impeded by delays in obtaining provincial coverage, which may be multifactorial but will ultimately result in a perceived 2-tiered system of availability such that only those patients with private health care insurance or those who are able to pay out of pocket may have early access to important therapeutic effects. Despite an apparent coordinated Canadian procurement process for new drugs, there remains significant inter-provincial variability in the timing and extent of public coverage, because provinces are not bound to purchase under this agreement. For example, British Columbia is the only province that does not have public coverage for eplerenone, which showed a 24% reduction in all-cause mortality and a 42% reduction in hospitalization for HF in the Eplerenone in Mild Patients Hospitalization and Survival Study in Heart Failure (EMPHASIS-HF) trial.²⁰

This complacency from federal and provincial regulatory bodies in providing timely access to HF therapies is perplexing given the magnitude of the HF epidemic and the associated costs incurred. A siloed budgetary framework lacking the flexibility to take advantage of opportunities to reduce hospitalization through increased spending on upstream HF therapies is not a patient-centred approach.

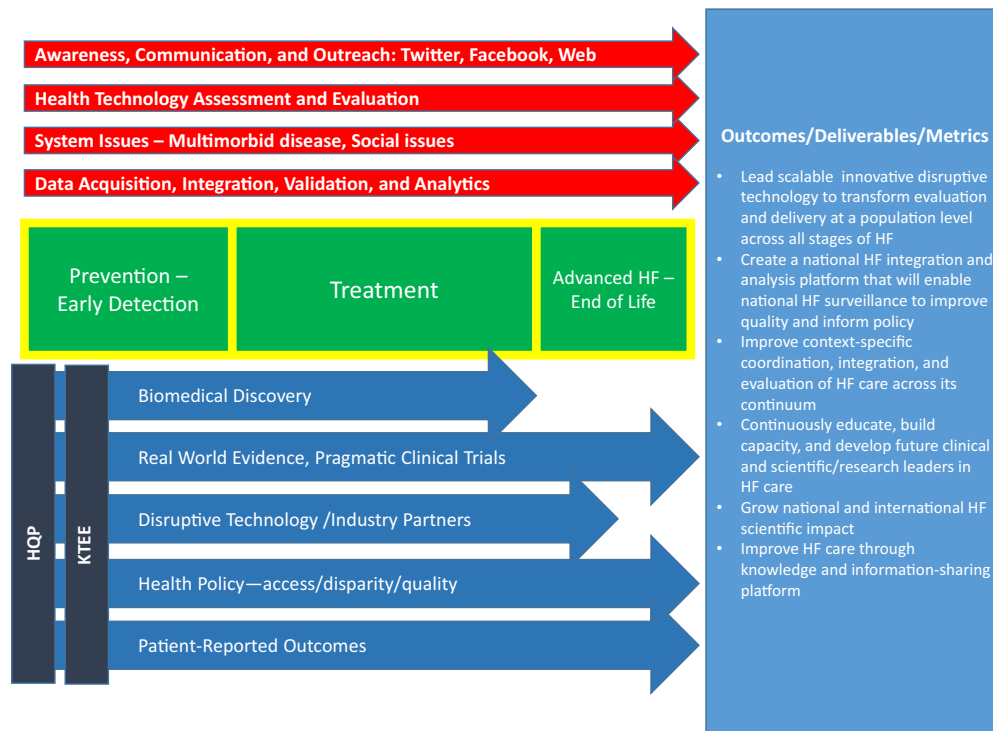


Figure 1. Strategic priorities of Technology, Research, Analysis, Network, and Systems For Managing Heart Failure (TRANSFORM-HF). HQP, highly qualified personnel; KTEE, knowledge and technology exchange and exploitation. (Courtesy of Dr Heather Ross.)

As new guideline-endorsed pharmaceutical and device therapies for HF emerge, Canadians should demand timely and equitable access to treatments that, in many cases, are lifesaving. This form of patient-driven advocacy has been very effective in ensuring timely access to new treatments in oncology and HIV; much can be learned and directly applied as a component of the HF lobby.²¹ Regulatory agencies should be transparent in their deliberations and held accountable for their decisions and any delays in access that may result. It is estimated that HF touches 1 in every 2 Canadians—this obviously is a large portion of the voting electorate.⁴

Recommendation

Health Canada and provincial ministries of health must commit to a consistent methodology for evaluation, implementation, and funding of new therapies across jurisdictions.

The Patient Voice in HF Treatment, Research, and Advocacy

Patients' active participation in their own treatment is critical to the success of any medical intervention designed to improve quality of life. Engaging patients as partners in their own care is especially important for those with HF, given the disease complexity, the high frequency of comorbidities, and the severe strain the disease places on patients and their families. HF self-management is key to improving patient outcomes.²²

Not infrequently, patients receive discordant recommendations from individual practitioners, which in turn undermine the patient's ability to successfully self-manage their conditions. Without an integrated care team and a

coordinated self- and comanagement strategy, patients can be left feeling defeated, isolated, depressed, and anxious about the prognosis, which may drive poorer outcomes and ultimately higher costs to the health care system.

Despite a significant body of evidence underpinning HF self-management as key to improving patient outcomes and reducing hospitalizations, to date the voice of the patient with HF has remained largely absent from the local, regional, and national conversation. The HeartLife Foundation (www.heartlife.ca), established in 2016, is a patient-led HF organization whose primary aim is to engage patients, families, and caregivers in the HF conversation and to elevate the patient voice by raising awareness and advocating for the systemic change necessary to improve access to knowledge and skill development, multidisciplinary support teams, and changing patterns of service as well as improving access to the financial, personal, and environmental resources needed to support and empower effective self-management.

Recommendation

Patients, their caregivers, and grassroots advocacy groups must be actively engaged in the transformation of HF service delivery in Canada and in the development of new knowledge to ensure that the future state meets the needs of those who are affected by this disease.

Driving Change Through Collaboration: A Call to Action

Harnessing the growing momentum in HF advocacy to improve outcomes for those with this disease will require a

Table 1. Summary of targets for HF health system redesign, recommendations, and enabling strategies

Target for health system redesign	Recommendations	Enabling strategies
Building systems of care	Collaborative development of regional and provincial care pathways for HF in collaboration with key stakeholder groups that leverage CCS HF guidelines and reflect local practice	Broad patient and other stakeholder engagement CCS HF guidelines and CCS key performance indicators Building new HF infrastructure and appropriately resourcing existing infrastructure Disruptive technology, communication, and outreach Technology to support HF prediction and early detection
National HF registry	Development of a national HF registry designed to measure key HF care processes and adherence to guideline-directed care and to track patient- and system-level outcomes across the care continuum	Data and analytics to support timely access to care and wait list management Real-time clinical decision support National health technology assessment and evaluation framework Personalized care through biomedical discovery, predictive modelling, pragmatic and clinical trials, and real-world evidence
Timely access to treatment	Commitment from Health Canada and provincial ministries of health to a consistent methodology for evaluation, implementation, and funding of new therapies across jurisdictions	Patient engagement and empowerment Data and analytics to support the impact of timely access to care Data and analytics to support costing and guide procurement Harmonized and patient-centred health service delivery National health technology assessment and evaluation framework
Patient and caregiver engagement	Engagement of patients and caregivers in the transformation of HF service delivery and in the development of new knowledge	Individualized and personalized care model Pragmatic and clinical trials with patient-centred end points Community-based and remotely accessible care delivery Equitable access to diagnosis and treatment Cross-institutional collaborations and broad stakeholder engagement Focus on behavioural and psychosocial determinants of health in HF populations

CCS, Canadian Cardiovascular Society; HF, heart failure.

comprehensive Canadian HF action plan built on strong stakeholder collaboration. It will require an alliance of organizations to mobilize resources and work together at regional, provincial, and national levels. These partners must include patient advocates such as HeartLife Foundation, professional associations, health systems administrators and policy makers, the Heart and Stroke Foundation, CCS, and the CHFS to meaningfully enable this work.

There are a number of priority areas that must be addressed through these collaborations as foundational steps to inform the development of an action plan. These priorities include system redesign policy, capacity planning, and strategies for complex change management; development of funding policies and allocation methods in relation to the human resources, technology, and infrastructure required for integrated HF care; integration of existing data sources with new data collection to enable performance management, measure adherence to best practice, and track observed and expected outcomes; deliberate and meaningful engagement of patients and caregivers in codesigning the system and ranking priorities for resource investment; seamless integration of research as a tool to both inform clinical care and support policy change; and building capacity through education and training of existing health care providers while concurrently partnering with professional associations on strategies to expand health human resources.

Well-informed and disruptive change is needed. As a foundational step for this call to action, and paramount to improving HF care and advocacy in Canada, a commitment

to fund a network of centres of excellence in HF is needed. In December 2016, the Canadian HF community had an initial meeting to establish **Technology, Research, Analysis, Network, and Systems For Managing Heart Failure (TRANSFORM-HF)** as a national HF consortium under the leadership of Dr Heather Ross (www.transformhf.com) and to develop a strategic plan targeting many of the barriers to optimal HF care that we have raised here. The focus of TRANSFORM HF will be to (1) address HF systems of care—from prevention and early detection to advanced HF care, (2) inform health policy, and (3) translate high-quality evidence into action (Fig. 1). TRANSFORM HF aligns with the recommendations presented here and may serve as a comprehensive vehicle through which they may be actualized. A summary of priority areas for HF health system redesign, recommendations, and enabling strategies is presented in Table 1.

The time is now for a comprehensive Canadian HF strategy. This intervention must be national in scope, integrated in fashion across the health system, and properly supported with funding, research, and policy. This will necessitate change in the organization and delivery of HF care, but it is the right thing to do for patients and the health system.

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