

# Heart Failure in the Young: The Patient Perspective and Lived Experience

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## Abstract

Heart failure (HF) is an often debilitating syndrome that carries a lifelong burden of increased morbidity and mortality. While most affected individuals are elderly with ischemic heart disease, there are subsets of younger individuals who will develop HF. In this group, non-ischemic causes of cardiomyopathy are more common, optimal therapies are less clear, and the personal and societal impact is often greater. The lived experience of younger patients highlights several unmet needs not addressed by large HF trials that influence survival, personal and financial wellness and return to activities of daily living. In Canada, there is an increasing focus on the patient perspective, especially amongst young individuals, when devising guidelines, policies and promoting advocacy in HF. This article describes the lived experience of HF through the case example of a young patient, summarizes the clinical challenges in this age group, and discusses opportunities to elevate the patient experience of care as a performance indicator.

## Resume

L'insuffisance cardiaque (IC) est un syndrome souvent débilitant qui entraîne une morbidité et une mortalité accrues tout au long de la vie. Si la plupart des personnes touchées sont des personnes âgées souffrant de cardiopathie ischémique, il existe des sous-groupes de personnes plus jeunes qui développeront une HF. Dans ce groupe, les causes non ischémiques de cardiomyopathie sont plus fréquentes, les thérapies optimales sont moins claires et l'impact personnel et sociétal est souvent plus important. L'expérience vécue par les jeunes patients met en évidence plusieurs besoins non satisfaits qui ne sont pas abordés par les grands essais sur l'HF et qui influencent la survie, le bien-être personnel et financier et le retour aux activités de la vie quotidienne. Au Canada, on accorde de plus en plus d'importance au point de vue du patient, en particulier chez les jeunes, lors de l'élaboration de directives et de politiques et de la promotion de la défense des droits en matière d'HF. Cet article décrit l'expérience vécue de l'HF à travers l'exemple d'un jeune patient, résume les défis cliniques dans ce groupe d'âge et discute des possibilités d'élever l'expérience du patient en matière de soins comme indicateur de performance.

Heart failure (HF) is a common, generally fatal, and often debilitating diagnosis that is increasing in prevalence.<sup>1</sup> In older individuals, ischemic and valvular heart disease predominates, whereas, in younger patients, viral triggers, genetic factors, congenital anomalies, and substance use play a greater role in

disease onset.<sup>1,2</sup> This latter group suffers from a dramatic risk of early mortality, but because it is comparatively rare (~1 in 2,000 incidence),<sup>3</sup> young patients with HF are under-represented in trials, clinical guidelines and policy documents. For example, the average ages of subjects enrolled in recent landmark trials

of HF ranged from 63–73 years old.<sup>4–6</sup> The evaluation of new HF therapies and treatment strategies has historically focused on morbidity and mortality endpoints, consistently overlooking the patient experience as a meaningful outcome of interest. As a consequence, and in the absence of robust clinical trial evidence, lived experience and patient perspectives are largely missing from treatment pathways and care algorithms.<sup>7,8</sup> In Canada, there is an emerging emphasis on metrics to define optimal medical therapy and appropriate diagnostic testing for HF,<sup>2,9</sup> but other quality indicators at the core of patient care remain absent – particularly the ability to listen, to explain, and to connect with patients, their families, and caregivers. Perhaps the group most affected by these limitations are young individuals who have relatively uncommon causes of HF and face unique social issues such as the challenges related to family planning, child care, career advancement, and personal relationships. These young HF patients, who are usually less frail, more socially engaged, and are more likely to recover, should shape this national conversation. Herein, we share the lived experience of a young patient with a history of advanced HF, outline the unique clinical challenges facing young HF patients, and summarize the current Canadian efforts focused on developing HF shared-care, advocacy, and community engagement.

## Patient Perspective

In July 2009, at the age of 23, I caught a cold. The cold, or what I thought was a cold, developed into the ‘flu.’ After visiting my family doctor, I was diagnosed with the ‘flu’ and a re-occurring case of asthma. I was prescribed an inhaler and rest. Like most individuals who see a family physician, I did what I was told. Over the next few weeks, the symptoms worsened to the point where I was sleeping at my kitchen table, taking breaks when walking two flights of stairs and suffering from chest pain. When the chest pain began, I decided to go to the local emergency department. It was there that I was diagnosed with severe advanced HF, with a left ventricular ejection fraction <15%.

After two weeks in the cardiac care unit, I was discharged home on medical therapy. A few weeks later, I was readmitted as my condition had once again declined. Just 3 months after my initial diagnosis, I had an implantable cardioverter-defibrillator (ICD) placed, and was listed for a heart transplant. Fortunately, I improved for a while and was taken off the transplant list, but still knew that one day, I would need a new heart. Over the ensuing years, I experienced times of stability and turbulence, including multiple ICD shocks, HF deterioration, a prolonged induced coma, and eventually a cardiac transplant.

My disease course was similar to that of many patients with HF but the journey was particularly poignant by my young age at diagnosis. Unlike those of more advanced age, who more

commonly develop HF, I felt that I had not yet lived a full life. Instead, I was only just beginning the next stage of my life. I had recently finished my degree, travelled the world, and was entering my first career. Like my peers, I was to move forward. That reality was no more. Here, I wish to focus on three aspects of my journey that are particularly unique to HF in the young.

First, I had to put my career and life goals on hold. While my peers continued to focus on my career and family, I focused on surviving. Between hospital readmissions, surgeries and ICD shocks, I was unable to commit to a full-time career. As a result, my goals of progressing up the corporate ladder, purchasing my first home, and continuing my travels were significantly delayed. HF was physically, emotionally, and professionally draining.

Second, HF is both a hidden and isolating disease. At 23 years old, I looked like I could conquer the world. Little did the world know, I could not walk up two flights of stairs, my ICD could trigger at any moment and I was on several medications with various side effects. People were often surprised that I was off work for medical reasons or couldn’t participate in a particular event or sporting activity. As time passes and as one misses events, the invites stop coming.

Third, I was presented with an opportunity to give back. As I will discuss next, HF at a young age has its benefits. As a young and motivated individual, I was provided the opportunity to change the discussion on HF. I was motivated to get better and shift the model of care for all Canadians. I was motivated to have my voice heard, so that heart patients, both young and old, could have a better expectation of care. I was able to discover a way to accomplish my goals and objectives in a new way.

This epiphany would not have been possible if my cardiologist had not taken the initiative to introduce me to other young HF patients. Upon speaking to these individuals, one with an ICD and one with a left ventricular assist device, I developed a sense of hope. A sense that, I was more than my disease. A sense that, with some hard work and dedication, I could live the quality of life I desired. Furthermore, I discovered the importance of peer-to-peer mentorship and talking to others with ‘lived experience.’ Interacting with like-minded individuals branched into new networks, friendships and ultimately the HeartLife Foundation ([www.HeartLife.ca](http://www.HeartLife.ca)), which I co-founded with Dr. Jillianne Code. The HeartLife Foundation is Canada’s only Patient Advocacy Charity focused on creating a better expectation of care for Canadians living with HF.

One of the foundational components of HeartLife is to educate patients and caregivers to help them understand HF, treatments, prognosis, and care continuum. From experience, I know that despite being educated and young, HF is a difficult disease to comprehend. Comprehension is further hindered when both physical and mental stress is present. When someone is

told they are in HF, or at least in my case, the question that often arises is, “Am I going to die?” When the initial shock subsides, 90% of the information that was told to me was forgotten. I was grateful for my support network, peers and team for continuing to reinforce the information. However, I have learned that I am the exception and not the rule. Education is the key to empowerment. Empowerment is the key to managing your disease effectively.

My progression through HF and eventual heart transplant has changed my perspective on life. I am now more healthy and able than ever. I am motivated by my experience to help change the way Canadians look at, talk about, and treat HF. I have learned that the face of HF is ever-changing and that each patient is unique. Therefore, the way we view each patient is unique and treatment must be patient centred.

### Heart Failure in the Young: Unique Clinical Challenges

Several unique aspects of HF in the young make it especially difficult to diagnose and to optimize quantity and quality of life. A clear paradox exists in young individuals: HF symptoms are less typical in nature and less severe, yet acuity at index presentation is greater and ejection fraction is lower.<sup>10</sup> Recent Canadian data show that in young patients (<45 years old), HF-related mortality is very high, approaching 30% at 5-years of follow-up.<sup>3</sup> However, since this group makes up a small proportion of HF cases (1.4%, or ~8,000 new cases per year)<sup>3</sup>, it may be underappreciated amongst physicians. The poor sensitivity of the physical exam, coupled with a reluctance to order tests in a young person deemed unlikely to have serious pathology, may further contribute to diagnostic delay.<sup>11</sup> Indeed, in the patient perspective described in the previous section, a life-threatening presentation of HF was initially misdiagnosed as the common cold. In the CHARM (Candesartan in Heart Failure Assessment of Reduction in Mortality and morbidity program) sub-study of young patients, HF hospitalizations were found to be more frequent, the cause of HF was more likely elusive, and adherence to guideline-directed medical therapy was lower.<sup>10</sup> These observations have a sound physiological basis, as blood pressure is normally lower in this age group, making orthostatic side effects greater, and decompensation more likely.<sup>12,13</sup> Although substance use disorders may be a presumptive cause of otherwise idiopathic HF in the young, they are rarely contributory.<sup>10</sup> Misattributing substance use as the cause of HF, and presuming therapeutic non-adherence in the young can adversely affect cardiac transplant eligibility and advanced mechanical circulatory support candidacy, which can erode patient trust, engagement and shared decision-making.

### Patient Engagement and Shared Decision Making

Patient engagement in HF is a major focus of advocacy initiatives in Canada. As noted in the patient perspective, the HeartLife Foundation is dedicated to education and the empowerment of patients, families, and caregivers of those living with HF in Canada. It is imperative that clinicians take time to regularly listen to patients’ description of symptoms, understand their experiences and values, and provide accurate information regarding the natural history of HF, including therapeutic options and prognosis. This open exchange of information allows for advanced care planning and shared decision-making. Too often, the possibility of admission to a critical care unit, the emergent need for mechanical circulatory support and/or cardiac transplantation, and a terminal event comes as a surprise to the patient and their family.<sup>11</sup> Risk of mortality is readily quantifiable, but the quality of life is an important measure that physicians underestimate when counselling patients.<sup>14</sup> Some patients may wish to sacrifice their probability of survival for incremental improvements in quality of life. Over time, and depending on candidacy for definitive therapies like cardiac transplants, these values and preferences may change. The American Heart Association recommends that these preferences be reviewed on an annual basis, at the beginning of any hospitalization, and selected clinical milestones, such as after the occurrence of ICD shocks.<sup>11</sup> Although these discussions may seem drastic to such young individuals, it is important to recognize that some therapies have weaker evidence in non-ischemic cardiomyopathy, and that decision-making should always be shared, especially when resources are limited (e.g., cardiac transplant). Revisiting these discussions at regular intervals is important, as many HF patients, even if young, have neurocognitive impairment, anxiety, and depression, different cultural and/or religious beliefs, and may experience changes to family dynamics that may alter their perspectives over time.<sup>7,8</sup> Time is often a limited resource, and clinicians must be sure to anticipate the extra time it takes to address these issues when seeing a younger HF patient. Emerging patient-led resources and advocacy groups can be an important source of information and support for these individuals.

### Moving Toward Patient Centredness in Canada

The Triple Aim framework, developed by the Institute for Healthcare Improvement, highlights the patient experience of care as a foundational pillar of high performing healthcare systems.<sup>15</sup> Similarly, the Institute of Medicine has identified patient-centredness as a strategic driver for transforming healthcare and a key feature of quality in health service delivery.<sup>16</sup> Despite being a cornerstone of quality care, as previously noted, patient-centredness is rarely evaluated in large clinical trials, and focus is placed on other dimensions of quality related to improving population health or cost-avoidance.

The Food and Drug Administration does not include a metric of patient-centredness among its suggested endpoints for HF drug development despite the broad availability of tools that can measure patient experience.<sup>17</sup> Beyond new therapies and treatments, there is a systemic lack of emphasis on patient-reported experience measures (PREMs) related to HF process of care, which may have significant variability based on patient age. Our current inventory of HF key performance indicators (KPIs) are largely related to in-hospital system-level processes and adherence to evidence-based medical therapy but direct measures of patient-centredness and the patient experience of care are missing.<sup>2,18</sup>

While the principles underpinning continuous quality improvement have been well articulated,<sup>19</sup> this requires performance measurement and establishment of a cycle that results in the development and implementation of practice guidelines. Currently, PREMs do not fit into the established rubric of quality improvement for HF. Thus, it is essential for KPIs that integrate patient-important outcomes to be: (a) measured and reported in clinical trials, and (b) serve as a meaningful component of HF health systems evaluations. In Canada, these should be included among the Canadian Cardiovascular Society's HF Quality Indicators, that act as a benchmark for best practice related to HF care nationally. Moreover, the value of patient-centred endpoints must be considered by regulatory bodies when evaluating public coverage of new therapeutic options for the treatment of HF, moving beyond traditional frameworks for assessing efficacy.

## Conclusions

The lived experience of patients with HF, especially younger individuals, is not adequately addressed by existing trials and consensus guidelines. As data continually emerge demonstrating that quality of life, mood, and anxiety disorders, as well as neurocognitive dysfunction, are predictors of morbidity and mortality, it is apparent that better knowledge translation of these outcomes, which are important to our patients, is needed. Strategies to reduce the burden of disease, beyond traditional clinical endpoints should be the focus of our new knowledge development. Moreover, the redesign of our health systems and clinical trials apparatus to ensure the perspectives of those with lived experience are foundationally integrated into our work must be a priority. In Canada, a growing patient-led foundation exists called HeartLife Canada, which is striving to address many of these unmet needs, but greater physician knowledge and engagement are also needed. By advocating for greater awareness of the HF lived experience, we may collectively improve the lives of thousands of young Canadians living with this challenging, and often invisible disorder.

## Disclosures

None relevant.

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