

MULTI-METHOD STUDY ON REFERRAL AND ACCESS TO HEART FUNCTION  
CLINICS

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A DISSERTATION SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN  
PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR  
OF PHILOSOPHY

GRADUATE PROGRAM IN KINESIOLOGY AND HEALTH SCIENCE  
YORK UNIVERSITY  
TORONTO, ONTARIO

February 2025

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## Abstract

Patients with heart failure (HF) experience significant benefits from receiving comprehensive outpatient care in specialized heart failure clinics (HF clinics). These clinics have demonstrated their effectiveness in reducing frequent HF-related hospital readmissions while maintaining cost-efficiency. Unfortunately, despite established guidelines recommending the referral of HF patients to these clinics, there exists a notable discrepancy in both access and utilization of this specialized care, creating issues of low and inequitable service utilization. The underlying reasons are largely unknown and under-researched. Therefore, this doctoral dissertation aimed to advance a scholarly understanding of factors influencing the referral decisions and access to HF clinics through a multi-method study. For this purpose, three inter-linked research studies were undertaken. Firstly, qualitative interviews were conducted with key stakeholders in HF care, including policymakers, clinic providers, and patients. This initial phase established a foundational understanding of the barriers preventing optimal access to HF clinic services. Secondly, recognizing that referring providers play a pivotal role in determining patient access to HF clinics, a mixed-method design was employed, using a sequential exploratory approach to delve into their perspectives on the challenges associated with referring patients to HF clinics. Finally, a cross-sectional survey approach was adopted to compare clinic perceptions of ideal referral criteria with those of referring providers. By identifying areas of agreement between both parties, strategies for consistent application were proposed. This dissertation contributes valuable insights for HF clinics and the broader HF community. The knowledge generated has the potential, when translated into practice, to facilitate appropriate patient access to essential HF services. The findings offer guidance to policymakers, healthcare providers, and HF patients,

aiming to optimize the utilization of HF clinic services, enhance the quality of care provided, and improve overall patient outcomes.

## Dedication

This dissertation is dedicated to loved ones and mentors who have been present throughout this entire journey, and those who had to leave before the end, you will forever be in my heart. Thank you for your unyielding love, support, and encouragement that have enriched my spirit and inspired me to become someone that can genuinely make a difference in this world.

## Acknowledgments

First and foremost, I would like to thank Almighty for all the blessings He's given me during the total process- the abilities and the opportunities and for the strength and guidance to accomplish the degree.

I would like to express my sincerest gratitude to the people who contributed to the completion of my dissertation, and who have been with me throughout these past four years during the pandemic. Thank you to my supervisor Professor. Sherry Grace, for this great opportunity to work with you, and for your constant support, guidance and encouragement. You have taught me a great deal which I will take with me as I continue in my future endeavors. In addition, I would also like to thank Dr. Edgell, Dr. Macpherson and Dr. Ghisi for accepting the invitation to be in my supervisory committee and providing invaluable continuous supports, feedback that keep me motivated. My sincere gratitude to my defense examination committee Dr. Phillips, Dr. Wong and Dr. O'Neill for their dynamic comments and fruitful discussion in improving the dissertation. Finally, I would like to thank members from the HF expert panel research team, HF patients, my colleagues and international collaborators of this project for their kind and endless support to accomplish this novel work.

Lastly, and most importantly, to my family and to my parents, I would not be where I am today without your encouragement, unconditional love, and guidance. You have always encouraged me to challenge myself and have faith on me.

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## CHAPTER ONE

In this chapter an overall introduction and literature review characterizing HF as a chronic condition is presented to support the need for specialized HF clinic services, including patient education on self management skills. Furthermore, the conceptual framework of this dissertation is described, as well as its objectives.

### INTRODUCTION

Cardiovascular disease (CVD) is the leading cause of the most significant increase in deaths worldwide, increasing from 12.1 million in 1990 to 20.5 million in 2021.<sup>1</sup> HF is a major health problem, affecting about 64 million people worldwide.<sup>2</sup> The risk-adjusted mortality after HF diagnosis is 8% at 30 days and 23% at 1 year.<sup>3</sup> HF has the second highest readmission rate of any health condition (17% within 30 days).<sup>4</sup> In addition, HF leads to hospital readmission rate of 13% in 30 days and 36% within one year globally,<sup>3</sup> resulting in the annual global estimated healthcare cost of around \$108 billion United States (US) dollars.<sup>5</sup> Therefore, HF imposes a massive burden on health care systems.

HF (or 'heart function') clinics can mitigate this burden by ensuring timely access to specialty, multidisciplinary integrated care in the community. The majority of HF care is provided by the primary care physician if not referred to the HF clinic, and patients often do not have the information on the available resources to live with this chronic condition. Since HF patients require frequent monitoring at the initial stage of their diagnosis to achieve optimal dose for guideline directed medical therapy (GDMT), those with usual care often experience unpredictable episodes of worsening symptoms and require hospitalization. There is no clear definition of HF clinic to our knowledge. However, Ontario Health (Previously CorHealth

Ontario) explained HF clinics as specialized, outpatient clinics offering key services aligned with Canadian Cardiovascular Society (CCS) HF guidelines and best practices by a multidisciplinary team to ensure a continuum of care from early disease management to palliative care.<sup>6</sup> The services include initial assessment and follow up monitoring, optimization of GDMT, self-management education resources, and advanced care planning and access to cardiac rehabilitation (CR) services.<sup>7</sup> The HF patients are referred to CR from HF clinics once they are deemed safe by the physician in the team. The HF clinics have been shown to reduce HF-related mortality by 15-20%, HF-related hospitalizations by 30-56%, and all-cause readmissions by 15-25%.<sup>8-10</sup> They are also shown to be cost-effective<sup>11</sup> which means better outcomes in those utilizing HF clinic care. Accordingly, referral to these disease management clinics is recommended by all major HF clinical practice guidelines.<sup>12-14</sup>

But the population impact of this simple but powerful intervention has been limited because so few receive it. At present, we do not know why in Ontario, only 10% of potentially-eligible HF patients receive care in HF clinics<sup>15</sup>. *Is it because they are not referred due to existing policies, providers' beliefs, preferences, or capacity issues? Is it patients' preference not to be referred? Are they referred but face geographical, financial, or other system or individual-level barriers to access? Or are they not accepted for care because of clinic providers' decisions?* Available research evidence suggests that the factors are multifactorial, interrelated, and poorly investigated.<sup>16</sup> Moreover, based on the established scientific evidence on the benefits of organized care, investigating the access gap to an intervention represents a real opportunity for improvement.

Therefore, given the importance and the complex nature of HF care, current challenges, underlying contextual and patient factors in accessing the HF clinics were evaluated at first

through qualitative research. Through this, a fundamental understanding of factors interplaying the key role were identified. This was followed by conglomerating the referring providers understanding of barriers in referring their HF patients to subspecialty HF clinic care in a timely manner. Finally, by incorporation of these findings and cross-checking with the clinic providers understandings, some recommendations were provided to promote utilization of HF clinic services. The dissertation is organized into six chapters. Chapter 1 presents a focused literature review followed by specific objectives of the three studies undertaken. Chapter 2 presents the results of a qualitative study of stakeholders entitled “Factors affecting referral and patient access to HF clinics in Ontario.” Chapter 3 presents the results of a mixed-method study entitled “Factors affecting Healthcare Provider Referral to HF clinics.” Chapter 4 presents the perspectives of clinics and referrers on ideal HF clinic inclusion and exclusion criteria and is titled “Heart failure clinic inclusion and exclusion criteria: cross-sectional study of clinic's and referring provider's perspectives.” Chapter five discusses the findings from all three studies with extended elaboration on the rationale for methodological choices employed for each study, strengths, limitations, and implications of such in context to HF burden in Canada. Finally, the concluding chapter proposed some recommendations to transform policy, refine current practices, and guide future research efforts to make significant impact in accessing HF care management.

## LITERATURE REVIEW

HF is a chronic, progressive, and incurable condition where the heart cannot pump sufficient oxygenated blood to meet the body's demands. It is characterized by episodes of

shortness of breath, coughing and wheezing, swelling of legs, and fatigue. HF patients often have a comorbid illness and impaired quality of life (QoL).<sup>17</sup>

## HF DISEASE BURDEN

About 100,000 Canadians are diagnosed newly with HF each year; 750,000 (4.3%) aged 40 years and over are currently living with it.<sup>18</sup> HF patients require frequent hospitalization and are six times more likely to die prematurely. It is the third most common causes for hospitalization in Canada, representing 2.3% of all hospitalizations in 2020.<sup>19</sup> Among medical conditions, HF has the 2<sup>nd</sup> highest readmission rate after cancer, and length of stay is double the average.<sup>17</sup> The global annual HF cost is increasing exponentially<sup>20</sup> and in Canada, it is expected to reach up to \$2.8 billions per year by the year 2030.<sup>18</sup>

Despite significant technological advancements in HF care,<sup>17,21</sup> the continuum of HF care remains poor. Due to their clinical complexity, patients with HF require frequent access to multiple levels of care within the health system making them vulnerable to fragmented care and poor patient prognosis and experience. The 5-year age- and sex-adjusted relative survival for HF (62%) is similar to that for most cancer patients (50-57%).<sup>22,23</sup>

## ORGANIZATION OF HF CARE

Current HF guidelines recommend lifestyle modifications (e.g., salt and fluid restriction, avoiding excessive intake of alcohol, smoking cessation, reducing overweight, and promoting physical exercise) and prescription of multiple medications requiring careful titration.<sup>12-14</sup> HF patients require specialized, continuous, and coordinated care by a multidisciplinary team, a team that includes a physician (family physician, internist, or cardiologist) or nurse practitioner, a pharmacist, and a registered nurse, with at least one care provider with specialized training in HF in Ontario.<sup>24</sup>

The provision of HF care through specialized disease management programs (DMPs) has been recommended for more than ten years in HF practice guidelines in Canada,<sup>12</sup> in the US,<sup>13</sup> and in Europe.<sup>25</sup> DMPs can include a *variety of interventions* (e.g., case management, patient education, telemonitoring, and CR) delivered in different *settings* (home, clinic). However, there is substantial heterogeneity in outpatient HF clinics in terms of geographic distribution, patterns of care based on specialist availability, diagnostic resources, and patient clinical characteristics even in within a country as investigated in Italy, Austria, and Canada.<sup>7,26,27</sup> Studies have shown that these specialized HF disease management clinics, with a focus on educating, empowering, and supporting patients with careful clinical follow-ups, are associated with a decrease in mortality.<sup>28</sup>

Cardiac rehabilitation is the gold standard of care for patients with chronic diseases. It is associated with reducing hospitalization and improving health-related quality of life, among other benefits in HF patients.<sup>29,30</sup> In addition, formal exercise training through CR is associated with reduced mortality, and increased functional capacity.<sup>31</sup> Access to CR services and its greater utilization through HF clinics are found to be significant to achieve these outcome benefits in HF patients.<sup>7</sup>

Patient education is a crucial component delivered alone or combined with CR in DMPs. There are five essential steps in delivering patient education intervention. These include knowing the patient's sociodemographics including, the highest level of education, identifying the type of learner (visual, auditory, read or write), assessing the patient's previous knowledge (health literacy level), needs assessment (learning needs, specific barriers), and then finally, planning the education intervention considering the goal set and continuous evaluation of patient's needs and revisiting them.<sup>32</sup> Evidence has shown that education intervention significantly influences

positive motivation for physical activity, dietary habits, smoking cessation, and improved psychosocial health in cardiac patients.<sup>33,34</sup> There are different patient education settings offered by HF clinics based on the available resources, such as one-on-one counseling (mostly), formal group education, telehealth counseling, and web-based education.<sup>7</sup>

The guideline recommendations for HF clinics are based on compelling evidence from more than 60 randomized trials and 15 meta-analyses reporting improvements in all-cause mortality by 15-20%, HF hospitalizations by 30-56%, and all-cause re-admissions by 15-25% compared to usual care (i.e., care provided by primary care physicians).<sup>9,10</sup> Effect sizes of such magnitude translate into many life years saved and would be considered revolutionary in any disease.

#### HEART FUNCTION CLINICS IN CANADA

Despite the established effectiveness of HF DMPs (also termed HF clinic) in reducing hospital re-admission and morbidity, the determinants of these program success are unknown due to the heterogeneity in the clinical context, organization, and contents of this complex intervention. There are several ways to provide HF DMP care, such as, home care, outpatient clinic interventions, structured telephone support, telemonitoring or a combination of two or more components.<sup>35</sup> In Canada, HF DMPs are administered through outpatient HF clinics, located within hospitals or stand-alone clinics in the community. HF patients are usually referred at hospital discharge or from primary care, making, on average four annual visits to HF clinics.<sup>36</sup> The 2010 Canadian Cardiovascular Society (CCS) HF guideline recommends that DMPs should be staffed by physicians, nurses, pharmacists, dietitians, or other healthcare professionals with expertise in HF; they should offer patient and caregiver education and “close” follow-up through telemonitoring or home care (*Class I, Level A recommendation*).<sup>37</sup> However, most HF clinics in

Canada are not staffed with various provider types as recommended. For example, small and medium-sized HF clinics employ nurses and nurse practitioners, but other allied HCPs are less frequently employed in small HF clinics.<sup>7</sup> There are at least 44 HF clinics identified in Ontario, 45 in Quebec, and 21 in British Columbia (BC) as reported in the most recent HF Resources and Services Inventory (HF-RaSI) in 2020-21.<sup>38</sup> Despite its established benefits, only one in ten HF patients are seen in HF clinics after hospital discharge.<sup>15</sup>

*Referral* to a healthcare service is dependent upon the provider's decision to refer, while *accessing* care after referral is dependent upon a patient's decision to attend. As a complex intervention (i.e., an intervention with multiple interacting components, multiple organizational levels, and outcomes<sup>39</sup>), mechanisms for referral, organization, and delivery of care through HF clinics are highly context-dependent. Moreover, along with many complex interventions, HF clinics are not implemented strictly as they are described in trial settings. Existing HF clinics are heterogeneous in terms of patient referral criteria, program structure, and patterns of care.<sup>10,16,40-</sup>  
<sup>42</sup> For instance, in 2020, it was found that Ontario HF clinics varied substantially in number and type of personnel, diagnostic capability, provided services, as well as service volume (e.g., 200-2000 annual visits.<sup>40</sup> Clinics also enrolled dissimilar patient groups (e.g., range of average age: 54-75 years), indicating variation in referral practices.<sup>36</sup> A recent national Canadian survey demonstrated a huge inconsistency in identifying the group of patients deemed most appropriate for HF clinics, leading to inequality in patient care, difficulty in access, and worsening patient outcomes and experiences.<sup>7</sup> The survey highlighted that there were gaps in infrastructure and personnel to deliver HF care optimally, leading to variable wait times exceeding >2 weeks in 41% of clinic respondents, resulting in poor transition of care.<sup>38</sup>

## CONCEPTUAL FRAMEWORK

To comprehensively understand the contextual, provider, and patient-level factors driving various patients' utilization of healthcare (i.e. utilizing HF clinic service), “Andersen’s Expanded Behavioral Model of Health Services Use<sup>43</sup>” is a suitable conceptual framework. It is the extension of the original “Andersen’s Behavioral Model of Health Services Use”. Andersen model is among the most dominant and widely used models for investigating healthcare access.<sup>44,45</sup> The original model was proposed in the 1970s<sup>46,47</sup> and has been modified over time.<sup>45</sup> The model has been applied in numerous studies to understand and improve healthcare access, including research on chronic disease management, healthcare disparities and patient decision-making.

According to the model, to improve access, understanding the contextual factors (i.e., an environment where services and care happen), the individual determinants (i.e. age, sex, economic status, disease severity), and the feedback mechanisms (i.e. factors influencing decision of using the services) are the pre-requisite.<sup>48</sup> Andersen’s model is a multi-level framework (Figure 1) in which both contextual and individual dimensions are again comprised of *predisposing conditions* (for use or non-use of services), *enabling conditions* (facilitating or impeding), and *need* (subjective and objective) *factors* that drive individuals to seek care or healthcare providers to recognize the need for care (here ‘*health behaviors*’).<sup>48</sup> (Table 1).

According to the model for HF clinic utilization, the key interplaying factors can be identified. For example, individual predisposing characteristics like younger age, having severe HF and a high education level could encourage the use HF clinics. Contextual or health-system level enabling factors like clinic availability, capacity, inadequate funding and long wait times could hinder access. Individual-level enabling resources including geographic proximity, and high-

income insurance coverage, could facilitate access. Individual-level perceived need to refer complex HF patients to HF clinics based on physician scope and training could influence the HF clinic utilization decision.

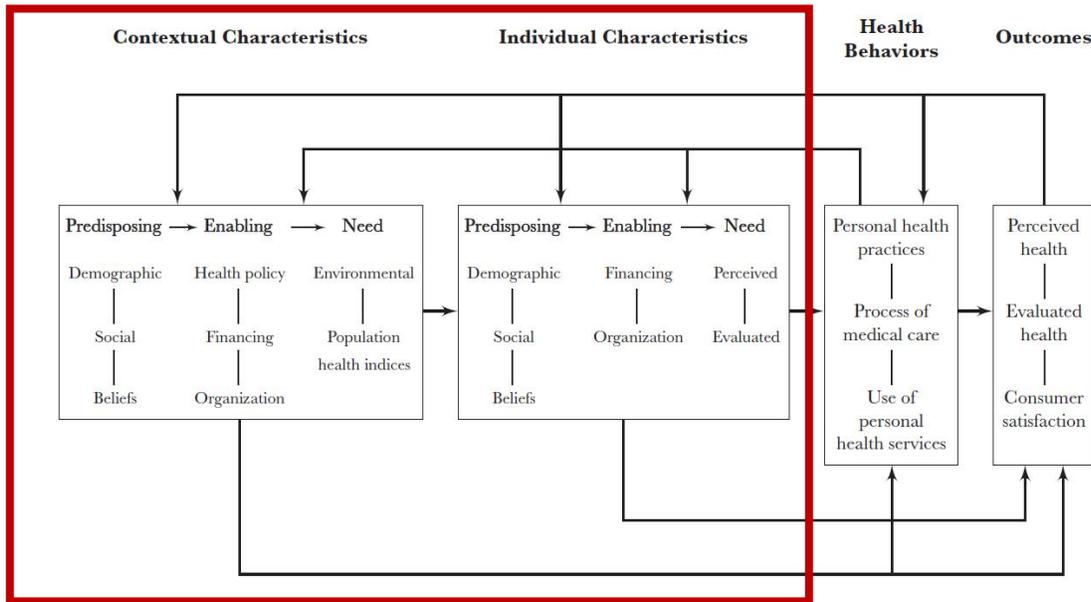


Figure 1: Andersen’s Behavioral Model of Health Services Use

Predisposing factors, which are present before the onset of illness, play a crucial role in individuals’ decisions to use healthcare services. While contextual-level predisposing factors such as organizational values and cultural norms are significant, it is the individual-level predisposing factors like age, gender, ethnicity, and beliefs that often take center stage in health service utilization decisions.

Similarly, enabling factors which incorporate economic and environmental elements, are both barriers and facilitators and the key influencers in the utilization of health services.

Examples of contextual-level enabling factors include health policies, financing, and resource

availability. However, the individual-level enabling factors like income, insurance, and cost of care often play a more direct and significant role in health service utilization.

Need factors are the objective and subjective aspects of the decision to use health services. Contextual-level need factors include health-related conditions of the environment and general population health (e.g., HF, other comorbidity burdens, aging population). Individual-level need factors include perceived health, functional status, the seriousness of the disease, symptoms, and consequences. Thus, Andersen’s model will be a powerful theoretical tool to guide our investigation of the health system, physician, and patient-level factors affecting HF clinic utilization (Table 1).

Table 1: Examples of contextual and individual factors relevant to HF clinic access based on Andersen’s Expanded Behavioral Model of Health Services Use

	<b>Contextual characteristics</b>	<b>Individual characteristics</b>
<b>Predisposing factors</b>	<b>Demographic:</b> demographic and social composition of communities (age, gender, marital status, etc.)	<b>Demographic:</b> age, gender
	<b>Social:</b> collective and organizational values (ethnic and racial composition, % immigrants, educational, employment, crime levels)	<b>Social:</b> education, occupation, immigration status, ethnicity, living/family states, social network and interactions
	<b>Beliefs:</b> community or organizational values, cultural norms and political perspectives regarding how health services should be organized, financed, and made accessible	<b>Beliefs:</b> attitudes, values and knowledge regarding health and health services that can influence perception of need and use of health services
<b>Enabling factors</b>	<b>Health policy:</b> public policies at all levels from local to national regarding services	Not applicable
	<b>Financing:</b> resources available within community for health services (per capita community income, and wealth, rate of health insurance coverage, relative price of medical care and other goods and services, and method of compensating providers, per capita expenditures for health services.)	<b>Financing:</b> income and wealth of individual to pay for services and the price for healthcare, insurance and cost-sharing requirements
	<b>Organization:</b> amount, varieties, locations, structures and distribution of health services facilities and personnel (ratios of physicians to population, office hours and location of	<b>Organization:</b> Individual’s regular source of care (private doctor, community clinic, emergency room), transportation, travel and wait time for care

	service, provider mix, outreach and education programs)	
<b>Need factors</b>	<b>Environmental:</b> health-related conditions of the environment (quality of housing, water, air, rate of occupational injury, disease and related deaths)	<b>Perceived:</b> perceived general health, functional status and symptoms; emotional response; perceptions on importance to seek care
	<b>Population health indices:</b> population health, general and condition-specific rates of mortality, morbidity and disability	<b>Evaluated:</b> physician assessed health status and need for care

## REFERRAL AND ACCESS TO HF CLINICS

Administrative data suggest that only 10.5% of Ontario HF patients are seen in an HF clinic within a year of hospitalization.<sup>28</sup> Based on another Ontario-based analysis, only 15% of hospitalized HF patients self-report referral to HF clinics within a year; of those, 85% report attending a clinic (Table 2).<sup>49</sup> A study in Quebec reported that after an ED visit, 29% of patients self-reported a referral to HF clinics at 6 weeks and 38% at 6 months.<sup>50</sup> Thus, 62 to 85% of potentially eligible patients are not referred to HF clinics.<sup>25,37,51</sup>

Table 2: Studies Assessing Predictors of Referral/Access to Multidisciplinary HF Clinics

Reference	Study Design & Patient Population	Results
<p><b>Grace et al<sup>49</sup>, 2012</b></p> <p><b>Ontario, Canada</b></p>	<p><b>Design:</b> Secondary analysis of a prospective study evaluating the comparative effectiveness of 4 referral strategies to cardiac rehabilitation programs.</p> <p><b>Population:</b> patients with primary or secondary diagnosis of HF admitted to one of 11 Ontario hospitals between 2006 and 2008 (n = 271).</p> <p><b>Other details:</b> i) used Andersen’s multi-level framework to investigate the predictors of access; ii) confirmed patient self-reported HF clinic access information by contacting the clinics.</p>	<p><b>At 1 year after hospital discharge:</b></p> <ul style="list-style-type: none"> <li>• 15.2% <u>referred</u> to HF clinics</li> <li>• 13% of the total study population (or 85% of referred) <u>accessed</u> HF clinics</li> </ul> <p><b>Predictors of HF clinic access at 1 year after discharge</b></p> <p><u>Patient-level factors:</u></p> <ul style="list-style-type: none"> <li>• <b>Education (completed high school or greater)</b></li> <li>• <b>Stress (greater)</b></li> <li>• <b>Functional status (greater)</b></li> <li>• <i>Not significant:</i> age, gender, income, living status, comorbidities (several tested), LVEF, functional class, past admissions</li> </ul> <p><u>Health system-level factors:</u></p> <ul style="list-style-type: none"> <li>• <b>HF clinic at the recruitment hospital site</b></li> <li>• <b>Referral to other DMPs</b></li> </ul> <p><i>Not significant:</i> hospital type</p>

<p><b>Feldman et al<sup>50</sup>, Canada 2013</b></p>	<p><b>Design:</b> A prospective cohort study aimed to determine if there was gender disparity in the referral of patients to specialized HF clinics</p> <p><b>Population:</b> patients admitted to 8 hospital EDs in Quebec from 2007 to 2010 for HF as the primary diagnosis (n=549)</p> <p><b>Other details:</b> i) used Andersen’s multi-level framework to investigate the predictors of referral; iii) investigated referral (self-report/medical chart) only but not access; iii) proportion referred and predictor factors are largely different from Ontario numbers as per Grace et al</p>	<p><b>After hospital discharge:</b></p> <ul style="list-style-type: none"> <li>• At 6 weeks: 28.6% <u>referred</u> to HF clinics</li> <li>• At 3 months: 33.5% <u>referred</u> to HF clinics</li> <li>• At 6 months: 37.6% <u>referred</u> to HF clinics</li> </ul> <p><b>Predictors of HF clinic referral at 6 months after discharge</b></p> <p>Patient-level <i>predisposing</i> factors:</p> <ul style="list-style-type: none"> <li>• <b>Male sex</b></li> <li>• <b>Age (in years)</b></li> </ul> <p>Patient-level <i>perception of need</i> factor:</p> <ul style="list-style-type: none"> <li>• <b>Systolic dysfunction HF (LVEF&lt;40%)</b></li> </ul> <p><i>Not significant: predisposing factors</i> – education, income; <i>enabling factors</i> - cardiologist/internist consult in ED, admission after ED, previous HF hospitalization, living with someone, prefers cardiologist follow-up; <i>perception of need</i> - comorbidity score, taking HF medication, Minnesota score.</p>
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<p><b>Gharacholou et al<sup>52</sup>, USA, 2011</b></p>	<p><b>Design:</b> A cross-sectional study aimed to determine factors associated with referral to HF disease management programs at hospital discharge</p> <p><b>Population:</b> patients hospitalized for HF in one of 235 hospitals participating in the get With the Guidelines-heart Failure program between 2005 and 2010 (n = 57,969)</p> <p><b>Other details:</b> referral was determined by using chart reviews</p>	<p><b>Referral at hospital discharge:</b></p> <ul style="list-style-type: none"> <li>• 19.2% <u>referred</u> (based on chart review) to HF disease management programs</li> </ul> <p><b><u>Predictors of referral at discharge</u></b></p> <p><u>Patient-level factors:</u></p> <ul style="list-style-type: none"> <li>• African American vs other race/ethnicity</li> <li>• Atrial fibrillation</li> <li>• Atrial flutter</li> <li>• Depression</li> <li>• Diabetes</li> <li>• Dialysis</li> <li>• Hypertension</li> <li>• ICD, CRT, CRT-D at admission</li> <li>• Heart rate at admission (per 5-bpm increase)</li> <li>• LVEF (per 5% increase, up to 50%)</li> </ul> <p><u>Health system-level factors:</u></p> <ul style="list-style-type: none"> <li>• <b>Hospital bed size (per 50-bed increase, from 150 to 550)</b></li> <li>• <b>Academic hospital</b></li> </ul> <p><i>Not significant:</i> age, gender, insurance type, systolic blood pressure, and sites with cardiac surgical capability</p>
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### *Factors affecting referral and access to HF clinic*

We do not know much about why only a small fraction of patients are referred to or access HF clinics in Ontario.<sup>16,53</sup> Andersen's behavioral model of health services use is particularly appropriate for effectively linking the relationships between contextual, provider and patient-level factors investigating access. Multiple factors (e.g., health system, provider, patient) are involved individually and in combination to determine who receives HF clinic care (Table 2). Therefore, a summary of what is known in this field based on the framework is provided below.

#### *System-level factors*

Only a few studies have examined health system factors affecting HF clinic use (Table 2). Among those, having an outpatient HF clinic at the discharge hospital site,<sup>49</sup> referrals to other DMPs,<sup>49</sup> hospital types,<sup>52</sup> and size<sup>52</sup> were shown to influence HF clinic utilization. It is important to note that healthcare policies can play a crucial role in creating an environment that either supports or impedes the utilization of HF clinics, thereby significantly influencing their accessibility.

In 2016, the Heart and Stroke Foundation of Canada called upon governments and healthcare providers to “support integrated systems of care” for HF and to “improve, expand and coordinate services across the continuum of care from prevention to diagnosis, treatment, management, end-of-life planning, and palliative care.”<sup>54</sup> Although HF clinics can undoubtedly fulfill this role, the policy responses aimed at facilitating this function differ among provinces. Alberta Health Services has taken a system-wide approach to enhance access by establishing an HF Network. BC developed a Provincial HF Strategy for creating new HF clinics to ensure consistency in HF care across providers, jurisdictions, and geographies.

Significant disparities persist in the accessibility to HF clinics in Ontario, characterized by prolonged wait times and inconsistent referral criteria.<sup>55</sup> In 2015, referral to an HF clinic became a recommended practice under Ontario's HF Quality-based procedures (QBP) for post-acute (community) HF episode of care<sup>56</sup>, the QBP, however, has never been operationalized. Considering the majority of HF care provided by PCPs, CorHealth's HF strategy proposes to implement 'hub-and-spoke' models for integrated HF care, assigning a more standardized role ('primary hub for intermediate complexity patients') to HF clinics (Figure 2). In this proposed model, low-risk patients could be managed in primary care settings (i.e., Level 1/ 'Spoke') in collaboration with HF care specialists, and, if required, referred to the next level for further management<sup>6</sup>. Furthermore, in 2018, one of the proposed standards for CCN's HF strategy calls for applying 'standardized referral criteria' to HF clinics aligned with the level of provided care (i.e., refer low complexity HF patients to 'spoke,' intermediate complexity to level 2 HF multidisciplinary team and high complexity to level 3 multidisciplinary team)<sup>6</sup>. *However, it is not clear that these initiatives can succeed without a deep understanding of the underlying structural issues associated with HF clinic referral and access.*

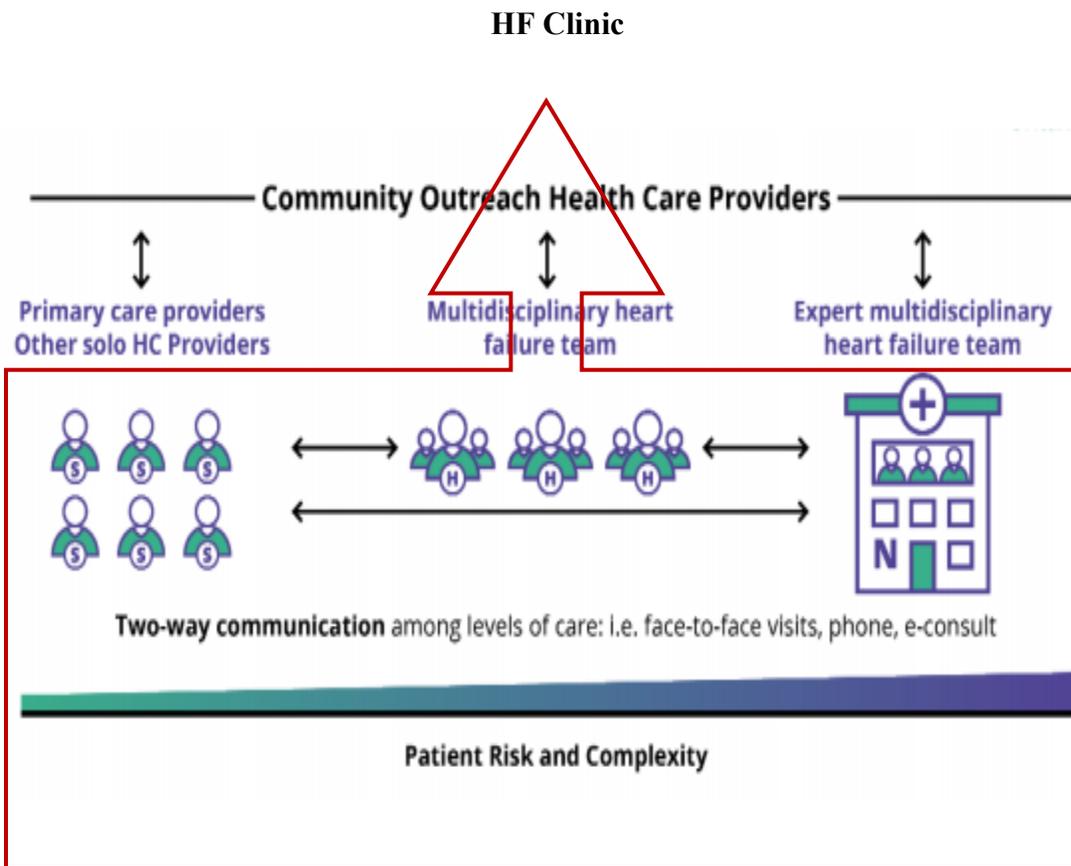


Figure 2. Example of a regional hub-and-spoke integrated model of heart failure care

(Image source: CorHealth Ontario. Minimal requirements and key clinical services for heart failure programs within a hub-and-spoke model of care. August 2018<sup>6</sup>)

### Referring provider-level factors

The literature on provider-level factors influencing referral to HF clinics is very scant. However, based on a study on referral to CR programs, physicians' decisions could be influenced by policies, guidelines, financial arrangements, and uncertainties in program effectiveness.<sup>57</sup>

Clinical guidelines can influence referral practices by setting referral criteria. Current guidelines are consistent in recommending referral to DMPs for optimal HF management, but provide inconsistent eligibility criteria for referral.<sup>25,37,51</sup> For example, the 2013<sup>51</sup> US and 2010<sup>37</sup>

Canadian guidelines recommend using multidisciplinary HF programs for patients at high risk of hospitalization, while the 2016<sup>25</sup> European guideline recommends access for all HF patients (Table 3). A 2014 CCS survey of HF experts identified 12 criteria to define a ‘high-risk’ HF patient (e.g., nonadherence, new-onset HF).<sup>58</sup> A 2015 Health Quality Ontario (HQO) review found no studies that established optimal patient referral criteria to HF clinics.<sup>59</sup> The subsequent HF QBP, however, provided a list of referral criteria, including high-risk HF (not defined), recurrent hospitalizations, concomitant ischemia, and multi-morbidity.<sup>56</sup>

Table 3: HF Clinic Referral Criteria in Practice Guidelines and Policy Documents

Author/organization	Document Type	Referral criteria
<p><b>Howlett et al<sup>37</sup></b> <b>(2010) Canada</b></p>	<p><b>Canadian Cardiovascular Society,</b> guidelines for the diagnosis and management of HF</p>	<ul style="list-style-type: none"> <li>• “Specialized hospital-based clinics or disease management programs staffed by physicians, nurses, pharmacists, dieticians and other health care professionals with expertise in HF management should be developed and used for <b>assessment and management of higher-risk (eg, two or more HF admissions in six months)</b> HF patients. <i>(Class I, level A)</i>”*</li> <li>• “<b>Patients with recurrent HF hospitalization</b> should be referred to a DMP by family physicians, emergency room physicians, internists or cardiologists for follow-up within four weeks of hospital or emergency department discharge, or sooner where feasible. <i>(Class I, level A)</i>”</li> </ul>
<p><b>Ezekowitz et al<sup>12</sup></b> <b>(2017) Canada</b></p>	<p>Comprehensive update on Canadian Cardiovascular Society guidelines</p>	<ul style="list-style-type: none"> <li>• “We recommend that <b>patients with either acute severe or chronic advanced HF and with an otherwise good life expectancy</b> be referred to a fully equipped cardiac centre for assessment and management by a team with expertise in the treatment of severe HF, including MCS (mechanical circulatory support) <i>(Class I, level B)</i>”</li> </ul>

	for the management of HF	
<b>Health Quality Ontario (2015) Canada<sup>56</sup></b>	<b>Postacute (Community) Heart Failure Episode of Care;</b> (Module 4: Discharge Planning/ Module 4a: Referral to Multidisciplinary Care)	<p>“We recommend that patients with HF who have the following characteristics should be considered for referral to an outpatient subspecialty clinic:</p> <ul style="list-style-type: none"> <li>• Patients with high-risk HF</li> <li>• Recurrent hospitalizations</li> <li>• New-onset HF that requires diagnostic or therapeutic intervention</li> <li>• Concomitant ischemia</li> <li>• NYHA Class III–IV</li> <li>• Asymptomatic or symptomatic patients with LVEF &lt;35%</li> <li>• Renal dysfunction (not requiring dialysis)</li> <li>• Multiple comorbidities</li> <li>• Concomitant RV dysfunction.”</li> </ul>
<b>Yancy et al<sup>51</sup> (2013) USA</b>	<b>American College of Cardiology Foundation/ American Heart Association,</b>	<p>“Multidisciplinary HF disease-management programs are recommended for <b>patients at high risk for hospital readmission</b>, to facilitate the implementation of GDMT (Guideline directed medical therapy), to address different barriers to behavioral change, and to reduce the risk of subsequent rehospitalization for HF (336,342–344). (<i>Class I, Level B</i>)”</p>

	Guideline for the Management of Heart Failure	
<b>Ponikowski et al<sup>25</sup></b> <b>(2016) European region</b>	<b>European Society of Cardiology,</b> Guidelines for the diagnosis and treatment of acute and chronic HF	“It is recommended that <b>patients with HF</b> are enrolled in a multidisciplinary care management programme to reduce the risk of HF hospitalization and mortality. <i>(Class I, level A).</i> ”

*\*Definition of high-risk HF patients by CCS (expert consensus) includes:* NYHA IIIb or IV symptoms; Frequent symptomatic hypotension; More than 1 HF admission (or need for outpatient intravenous therapy) in past year; Recent HF hospitalization especially in past month; Increasing creatinine level, especially GFR < 30 mL/min; Nonadherence to therapy for any reason during titration of HF medications (ACEi/BB/ARB/MRA); New-onset HF; Complication of HF therapy; Need to down titrate or discontinue BB or ACEi/ARB; Concomitant and active illness (eg, high-grade angina, severe COPD, frailty); Frequent ICD firings (1 month).

HF clinic-level factors:

Clinic-level factors such as capacity, location, integration with other DMPs, and clinic-specific referral (intake) criteria can also influence referral and access. Since there are no standardized criteria, HF clinics set their own referral criteria, as often displayed on their referral forms. Thus, HF clinics can have variable criteria for new and ongoing patients. In addition, the HF clinic’s involvement in the integrated funding models for HF such as the Ministry Of Health [MOH]-funded demonstration projects in Ontario that aim to fund a full episode-of-care, i.e., both in the hospital and at home, can also influence the referral criteria and the process.<sup>60</sup>

### Patient-level factors

To our knowledge, there have been three studies on HF clinic utilization, with 2 in Canada and the other in the USA. Based on the Quebec study, the patient-level factors of referral within 6 months of discharge included male sex, younger age, and having systolic dysfunction.<sup>50</sup> The Ontario study reported higher education, lower perceived stress, and lower functional status as factors related to access to HF clinics within 1-year of discharge.<sup>49</sup> Age and gender were not significant predictors in this study.<sup>49</sup>

The US-based study reported that predictors of utilizing HF clinic services included race/ethnicity and several comorbidities that were not significant in the Canadian studies.<sup>52</sup> Differences between the patient-level factors highlight again that utilization is highly variable and context-dependent.

### *Critical appraisal of past research*

There have been two reviews investigating mechanisms and factors influencing HF clinic use; one is Global<sup>53</sup> and the other is in Canada.<sup>16</sup> The first one was a realist review, including 29 papers from five countries (predominantly North America; 9 from Canada) which identified that lack of clinic capacity, geography, and funding arrangements were among the contextual factors and patient clinical characteristics, social determinants of health and clinic characteristics were important mechanistic processes that could explain the structural problems in optimal use of HF clinics.<sup>53</sup> The Canadian narrative review investigated the availability, nature and patient characteristics of HF clinics. They concluded that while multi-level factors play a role, including hospital characteristics, type of treating provider, inconsistent referral criteria, and patient sex/gender, which are related to low and inequitable use of clinics, involving cardiovascular nurses could promote greater and appropriate access to HF clinics.<sup>16</sup>

There were two Canadian studies, one based in Ontario and one in Quebec, that investigated factors predicting referral to HF clinics<sup>49,50</sup> (Table 2). Both studies used Andersen's Behavioral Model of Health Care Utilization<sup>61</sup> but applied different methods. The primary aim of the Quebec study was to test gender bias in referrals to HF clinics.<sup>50</sup> It evaluated referral but not access and did not investigate any system or provider-level factors. The Ontario study assessed the predictors of access but not the referral.<sup>49</sup> The identified predictors did not overlap except the functional status (see 'Patient-level factors' above). Neither study investigated the reasons for not accessing clinics considering system or provider-level factors and did not consider time to access the program. Another study conducted in the US, was focused on only referral at hospital discharge and reported a completely different set of predictors,<sup>52</sup> like patients who were treated in larger academic hospitals, diagnosed with atrial fibrillation, and had the cardiac devices implanted were referred to HF clinics more (Table 2).

As a complex intervention, referral, organization, and delivery of HF care through HF clinics are highly context-dependent. Moreover, Andersen's Behavioral Model for Healthcare Use provides a robust framework for understanding the factors that influence individuals' decisions and contextual characteristics to access healthcare services. The model highlights the complex interplay of individual characteristics, societal conditions, and healthcare system organization, by emphasizing predisposing, enabling, and need factors at both individual and contextual levels. Although previous reviews reported that quantitative approaches have been extensively utilized in this model to analyze various healthcare utilization patterns, there is a growing recognition of the value of qualitative research in uncovering the nuanced experiences and perceptions of individuals with lived experiences navigating the healthcare system.<sup>62</sup> Therefore, conducting qualitative studies can delve deeper into the contextual and personal

factors that shape decision-making regarding HF clinics, revealing insights into barriers and facilitators of access that may not be captured in quantitative surveys. This approach would enrich the hidden understanding of healthcare utilization and inform the development of more effective, needs-based interventions tailored to diverse populations. In addition, healthcare in Canada is governed provincially, leading to different provinces having unique rules for healthcare system. Among the provinces, Ontario is the most populated one, with 15 million people and a rich diversity shaped by significant immigration and regional variations. This has led to increased challenges in managing the rapidly growing diverse population with various cardiovascular morbidity.<sup>63</sup> Thus, the proposed research investigated the current referral and access gap to HF clinics in Ontario through a qualitative approach to obtain in-depth insights into HF care, followed by the administration of pan-Canadian surveys to identify the patterns and trends in accessing HF clinic. This comprehensive, multimethod evaluation would allow a richer interpretation to make recommendations to improve HF care and outcomes.

#### EXPERT ADVISORY COMMITTEE

A research team was formed led by the author of this dissertation (TM), including other trainees (AA, AH), and mentored by the supervisor (SG). The research team worked in collaboration with expert panel in HF and the PhD supervising committee. The members of the expert advisory committee and their expertise were elaborated in Appendix A. In brief, there were five members in the advisory committee specialized in HF research. Dr. LA is a clinician researcher with multiple papers on snapshot of HF care in Canada affiliated with Toronto Health Economics and Technology Assessment (THETA). Dr. MM is cardiologist with advanced training in HF care and representative of Ontario HF clinic provider, affiliated with Assistant Professor of Medicine, University of Toronto. Dr. DL who has expertise in HF epidemiology and

outcomes, was acting as the representative of Ontario HF clinic referrer in this project, also affiliated with University of Toronto as Professor of Medicine, and Senior Scientist, Toronto General Hospital Research Institute (TGHRI). Dr. KH was acting as the representative of Ontario HF policymaker, Clinical Strategist, CorHealth Ontario. Finally, Dr. SV as a non-Ontario expert / Canadian Heart Failure Society Board Representative and HF patient partner, affiliated with University of British Columbia, BC as an associate Professor, and Medical Director, HeartLife Foundation, Canada.

## DISSERTATION PURPOSE, OBJECTIVES AND HYPOTHESES

The purposes of this dissertation were (1) to explore the gaps in physician referral and patient access to HF clinics, through an in-depth understandings of interplaying key factors and then (2) to propose strategies to address these gaps, fostering improved referral communication and increased utilization of HF clinics.

This dissertation combines three papers with specific objectives, as described below:

### **Paper 1: Factors Affecting Referral and Patient Access to Heart Function Clinics in**

#### **Ontario: A Qualitative Study of Stakeholders.**

(1) To investigate factors affecting referral and access to HF clinics from multiple stakeholders' perspectives, namely policymakers (PMs), providers in HF clinics, and patients with HF; and

(2) To identify the facilitators to improving appropriate use.

*Hypothesis:* It was hypothesized that there are multiple factors influencing providers' and patients' decisions on accessing to life saving HF clinic care (such as, referral appropriateness and timeliness, clinic's insufficient capacity, patient's socioeconomic status, etc.)

**Paper 2: Factors affecting Healthcare Provider Referral to HF Clinics: A Mixed methods Study.**

- (1) To investigate the factors affecting healthcare provider referral to HF clinics,
- (2) How this might differ by provider specialty and was impacted by the COVID-19 pandemic.

*Hypothesis:* It was hypothesized that the referring providers would face some unique challenges while referring their patients and with pandemic this might worsened considering limited healthcare workforce.

**Paper 3: Heart failure clinic inclusion and exclusion criteria: Cross-sectional study of clinic's and referring provider's perspectives.**

- (1) To characterize the perceptions of providers at clinics regarding actual versus ideal HF clinic inclusion and exclusion criteria; and,
- (2) How these relate to the referring clinician perspectives of ideal criteria.

*Hypothesis:* It was hypothesized that both groups of providers would have similar perspectives on the ideal HF clinic inclusion and exclusion criteria with consideration of clinical practice guideline recommendations.

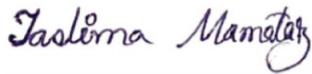
## **CHAPTER TWO**

PAPER ONE: Factors Affecting Referral and Patient Access to Heart Function Clinics in Ontario: A Qualitative Study of Stakeholders.

CERTIFICATE OF AUTHENTICATION

**Mamataz T**, Fowokan A, Hajaj AM, Asghar A, Abrahamyan L, McDonald M, Harkness K, Grace SL. Factors Affecting Referral and Patient Access to Heart Function Clinics in Ontario: A Qualitative Study of Stakeholders. CJC Open. 2023 Mar 9;5(6):421-428. doi: 10.1016/j.cjco.2023.03.002.

The candidate reached out the potential interviewees by collecting email addresses, scheduled interviews after securing informed consent and then conducted the interviews along with the senior researchers through MS Team. She was responsible for taking notes of non-verbal communications during the interviews, transcript cleaning and data analyses in NVivo. Finally, the candidate prepared the first draft with themes and quotes and incorporated subsequent revisions; she also undertook the journal submission processes.



Signature: \_\_\_\_\_ Date: Jan 04, 2025

Taslima Mamataz



Signature: \_\_\_\_\_ Date: Jan 04, 2025

Sherry L. Grace

## ABSTRACT

**Background:** Although heart failure patients benefit from multidisciplinary care in HF clinics, utilization is suboptimal and inequitable. This study investigated factors influencing referral and patient access to HF clinics from multiple stakeholders' perspectives, namely policymakers, providers at HF clinics, and patients.

**Methods:** In this qualitative study, semi-structured interviews with a purposive sample of Ontario stakeholders were conducted in February-June 2020 and July-December 2022 (paused due to pandemic) via the Teams platform. Interview transcripts were analyzed concurrently using systematic text condensation with Nvivo. Two authors coded individually, with disagreements discussed with the senior author.

**Results:** Interviews with providers at 7 HF clinics (6 physicians, 1 nurse), 6 policymakers, and 4 patients were completed before saturation; 5 themes emerged. First, with regard to health system organization, stakeholders reported gaps related to continuity of care, limited capacity, and insufficient funding. Second, with regard to referral appropriateness and timeliness, subthemes were related to unclear referral criteria, varying clinic scope, and delays in triage, testing, and time-to-visit. The third theme was related to clinic characteristics, and raised issues regarding varying clinic services and composition of healthcare professions/expertise. The fourth theme regarding patient factors was related to comorbidity/frailty, socioeconomic status, barriers due to location (parking, traffic), and affinity to specific providers. The final theme was related to the COVID-19 pandemic and concerned increased referral volumes, loss to follow-up care, transition to online delivery modalities, and patient refusal of in-person visits. The issue of the need for many facilitators to improve HF clinic referral and access was raised.

**Conclusions:** Resources must be provided, and stakeholders brought together, to standardize and integrate the heart failure care continuum.

## 1 INTRODUCTION

Heart failure (HF) is a chronic, progressive and complex disease affecting close to 65 million people worldwide.<sup>64,65</sup> About 100,000 Canadians are newly diagnosed with HF each year, and 750,000 are currently living with the condition.<sup>18</sup> As in other high-income countries, despite advancements in pharmacologic and device therapies, the epidemic of HF is rising alarmingly, with mortality and readmission rates alarmingly high.<sup>66</sup> Given there is no cure, secondary prevention is the goal; clinical guideline recommendations to reduce disease progression and optimize quality of life are many.<sup>14,67</sup> However, it is challenging for providers to achieve optimal medical therapy for many reasons, including contraindications to therapy, dynamic changes in the clinical status of patients, comorbidities, and inertia.<sup>68-70</sup> Moreover, it is challenging for patients to achieve optimal self-management as it requires sustained health behavior changes (e.g., daily medication adherence, weighing, diet, exercise, and symptom monitoring), which must be implemented in the context of psychosocial, cultural, environmental and economic barriers.

While their composition and structure varies,<sup>7</sup> HF clinics are comprehensive outpatient disease management clinics facilitating rapid care access to prevent acute decompensation, staffed by a multidisciplinary team of sub-specialties.<sup>13,24</sup> HF clinics provide assessment, patient education on self-management skills, medication optimization, and follow-up as needed. Some clinics are more specific to assessment for devices or advanced transplantation candidacy for example. HF clinics have been shown to reduce HF-related mortality by 10-15%, HF-related hospitalizations by 30-56% and all-cause readmissions by 15-25%.<sup>71,72</sup> and also shown to be cost-effective.<sup>11</sup> Therefore, guidelines from major cardiac societies globally recommend referral to these clinics,

although there is no consensus in referral criteria regarding which patients would be best served.<sup>12,16</sup>

Despite established benefits, only approximately 10% of patients receive care from HF clinics, and there are notable inequities.<sup>53</sup> For instance, female-identifying and older patients, living in rural areas, and those of lower socioeconomic status less often receive care.<sup>16</sup> There are issues related to referral (i.e., action required on behalf of healthcare providers and clinics) and access (i.e., action required by patient to go to appointments) that impede optimal use of these services. These challenges were exacerbated by the COVID-19 pandemic, when access to cardiac care was significantly reduced.<sup>73–76</sup> A previous review by our group revealed minimal research investigating why patients are not accessing HF clinics.<sup>53</sup> Moreover, a recent survey of HF clinics across Canada recommended the development of explicit patient and risk-based guidance on who should or should not be seen in an HF clinics (including mode of delivery, which is very germane in the current COVID-19 era).<sup>7</sup> Therefore, the objectives of this study were to (a) investigate factors affecting referral and access to HF clinics from multiple stakeholders' perspectives, namely policymakers (PM), providers in HF clinics and patients with HF, and (b) identify facilitators to improve appropriate use.

## 2 METHODS

### *2.1. Design*

This qualitative study was informed by an eight-member Expert Panel (Appendix A) comprised of a patient organization, an HF administrator, HF physician sub-specialists, HF clinic provider, members of leading HF committees in the country, a scientist with content expertise, and methodologist. It was approved by the institutional review boards of University Health Network (CAPCR ID#19-6171) and York University, Toronto. All participants provided written

informed consent (Appendix H). Interviews were conducted from February–June 2020, and then halted due to the COVID-19 pandemic. Interviews resumed in July 2022, and continued through December. The study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines,<sup>77</sup> and best practices to ensure the rigor of the qualitative methods were followed.<sup>78</sup>

## *2.2. Setting & Participants*

The study was conducted in Ontario, Canada, where healthcare delivery is under provincial jurisdiction. It is estimated that there are 36 HF clinics in Ontario.<sup>16</sup> Each clinic serves a median of 200 patients/ year, with an estimated 2000 annual patient visits. Overall, 157 HF physicians and 60 nurse-practitioners (NPs) are providing care in these clinics. However, clinic services vary, with less than half offering implantable defibrillator or cardiac resynchronization therapy expertise, and only one-tenth with expertise in heart transplant or mechanical circulatory support. In addition, while most clinics optimize guideline-directed medical therapy along with medication and dietary consultation, remote monitoring and community partnerships for home visits are still very limited. Nevertheless, advanced care directives and end-of-life planning discussions are offered in most of these clinics.<sup>7,15,40</sup>

Three stakeholder groups were included and purposively sampled, namely: Ontario PMs/administrators (e.g., Ministry of Health, Health Quality Ontario, CorHealth Ontario / now Ontario Health, heads of major Divisions of Cardiology), healthcare providers currently working in HF Clinics (e.g., physicians, nurses), and patients with HF (including those who did and did not access clinics). Participants were interviewed until theme saturation was achieved.

PMs are those who plan, organise, direct, and coordinate health services. For recruitment of Ontario PMs, CorHealth Ontario's Cardiac Hospital Administration committee members were

contacted. HF clinics were identified through a previous environmental scan<sup>15</sup> and contacted through our Expert Panel members.

HF patient participants were reached through our patient partner organization the HeartLife Foundation(<https://heartlife.ca/>), social media, and the Ted Rogers Centre for Heart Research's Heart Hub. Patient inclusion criteria included: living with HF in Ontario and English-language proficiency. Those with significant cognitive impairment, and lack of willingness to have the interview recorded were excluded from this study.

As interviews proceeded, expert panel members were asked to identify potential interviewees with characteristics that differed from participants (e.g., different types of institutions, professions, sex). For HF patients, attempts were made to recruit both males and females, and to have representation of patients living in and outside urban areas.

### *2.3. Procedure*

Semi-structured interviews were conducted through Microsoft Teams; face-to-face interviews were avoided considering COVID-19. Potential interviewees were emailed an invitation to participate (Appendix E); non-responders were contacted again two weeks later. A reminder email was sent to the interviewees a few days before the interview, including the interview questions.

The interview questions were shared on screen throughout, and all parties had their cameras on. Interviews were audio-recorded, but also video-recorded so that non-verbal communication could also be considered in analyses. Facial expressions, hand gestures, tone of voice, and pauses were noted in each interview. Interviews were led by a senior member of the team, and a trainee observed to take notes. Interviews were approximately 45 minutes in length.

## *2.4. Materials*

To capture the diverse array of perspectives by stakeholder type, a separate semi-structured interview guide was designed for each (Appendix B). The interview guides were developed based on our reviews of literatures<sup>16,53</sup> and information on HF clinic care in the province.<sup>7,40</sup> Input from the expert advisory panel was solicited and incorporated into the final the interview guides. When data collection resumed in 2022, questions about the impact of the pandemic on HF clinic access were added to the interview guides.

## *2.5. Analyses*

First, each interview transcript was cleaned to ensure accuracy and anonymity. Then, data coding was performed individually by two authors concurrently with data collection. The data were analysed using NVivo version 12. Given the three stakeholder groups, transcripts were analyzed using systematic text condensation.<sup>79</sup> Each transcript was read thoroughly to obtain a general impression. Then, the meaning-bearing units that described the same central meaning were identified by going through each transcription systematically. Next, a codebook was developed based on extracted meaning units, with constant comparison applied to identify, expand, or merge themes across the stakeholder groups.<sup>79</sup> All codes were subsequently read through and analyzed for similarities and differences across participants and stakeholder groups. This was followed by a reconciliation meeting to review and come to agreement on the coding for each transcript, as well as the text condensation. Any disagreements were reconciled through discussion with the senior author. The identified themes and sub-themes-- illustrated by quotes from the interviewees-- were then reviewed by the Expert Panel for confirmation, which adds credibility to the findings.

### 3 RESULTS

A total of 17 interviews were conducted before saturation was achieved; five were conducted post-pandemic. Characteristics of the seven HF clinic providers, six PM and four patient respondents are shown in Table 4. Analysis revealed five themes with associated sub-themes, as illustrated in Figure 3. With the addition of the COVID-19 question, an additional theme was identified; there were not many other differences in responses before and after the pandemic. Exemplary quotes are shown in Table 5. Facilitators to address challenges identified are shown in Table 6.

First, with regard to health system organization, sub-themes of gaps in continuity of care, limited capacity and insufficient funding were raised. With regard to the former, respondents spoke to the importance of timely identification/ diagnosis of HF patients by a primary care provider, who would then refer to an internist or cardiologist. The specialist would then refer to the HF clinic where appropriate. Emergency and primary care physicians must be aware of HF clinic availability as well, to support appropriate and equitable referral of patients.<sup>80</sup> With regard to capacity/ volumes, clinics should be located based on regional incidence of HF, with capacity and expertise to match the population. While location is becoming less important with the increased availability of virtual care, some visits should be in-person. Moreover, there was wide variation in terms of capacity of each HF clinic, and their approach to managing referrals when they were at capacity, as well as variation in terms of clinic approach to discharging patients; some kept patients through to end-of-life, others for 1 year or until they were stable / fully titrated on medical therapy, to create capacity for new patients. Finally with regard to funding, the main issue was that there was no way to bill directly for clinic services except for physician time. Thus, the funding and resources (e.g., overhead, administrative support, nurses) to run the

clinic were coming from the global hospital budget, which was often insufficient and perceived as undependable.

Second, with regard to referral appropriateness and timeliness, sub-themes related to unclear referral criteria, varying clinic scope, as well as delays in triage, testing and time-to-visit. Referral criteria/scope varied widely by clinic, often depending upon the expertise of the physicians. As outlined above, many required a patient be seen by a cardiologist first; other clinics based acceptance on number of hospital visits, medication factors (including adherence), or need for advanced therapies, for example. These criteria were not explicitly stated in many cases—neither at the clinic, nor with referring clinicians; this often resulted in receipt of “inappropriate” referrals, which many clinics then spent time re-directing elsewhere. There was lack of consensus on what the clinic referral criteria should be, with some clinics tightening or changing criteria over time to reduce unmanageable referral volumes, again often without targeted communication to the referral base. With regard to appropriateness, many clinics perceived they are not receiving referrals for the patients who are most in need, but have not had the ability to test this directly. The timeliness/efficiency of the referral process was also perceived as deficient. Clinics were aiming to reduce re-admissions, particularly with the government focus on reducing the 30-day rates, thus patients need to be seen well before 30 days from hospital discharge. However, often clinics received incomplete referrals, which creates delays in assessing appropriateness for HF clinic services as well as determining priority.

The third theme related to clinic characteristics, raised issues of how variation in clinic services and composition of healthcare professions / expertise impacted patient referral. As outlined above, clinics varied in the information required to consider and accept patients. They also had different modes of accepting referrals, with more options preferable. Services also

varied from clinic to clinic; for example, some clinics focused on candidacy for devices or advanced therapies, while others focus on more general HF care, such as medication titration. With regard to the latter, the nature of the healthcare providers also varied and their number. Some had one physician, others many, who could be specialists or sub-specialists. Others had a mix of nurses and specialist nurse-practitioners. The nature of the allied health care complement and administrative staff varied as well, all impacting the number and type of patients that could be seen and when. Finally, they also varied in how they covered physician cancellations, again impacting access to care.

The fourth theme regarding patient and social factors related to comorbidity / frailty, socioeconomic status, barriers due to location and affinity to specific providers. For instance, some patients had physical limitations, necessitating accompaniment by a caregiver. Clinic location had implications for proximity to home / travel time and conditions, parking cost and availability, as well as traffic density. Patients preferred providers with shorter wait times-- for both an appointment date, and then on the day of the appointment, they wanted the provider to be on time. Some patients lacked primary care providers or preferred the subspecialty care at the HF clinic to their cardiologists/referring physicians, so were pursuing care based on provider preference / bedside manner, rather than appropriateness.

The final theme related to the COVID-19 pandemic concerned increased referral volumes, transition to online delivery modalities, and loss to follow-up care, exacerbated by patient refusal of in-person visits. Some patients were trying to avoid the healthcare system for fear of contracting the virus, or could not get in to see primary care providers. Relatedly, clinics reported more referrals, many of which were not appropriate. Clinics reported patients or caregivers refused necessary in-person visits on some occasions, including situations where

informal caregivers were not vaccinated or did not want to mask, and hence would not be allowed entry to the clinic where they were located in a hospital with such infection control policies. Where virtual appointments were appropriate, capacity to treat these patients hinged on the technological capability of not only the clinic, but also patient's access, in terms of hardware/devices, software, technical support and verbal communication skills. Many older patients joined the virtual appointments with support of their adult children.

#### 4 DISCUSSION

This was the first study to investigate multi-level factors in referral and access to HF clinics in a public health system, including during the COVID-19 pandemic.<sup>81</sup> This was conducted in Ontario, Canada where urgently needed, given a recent report from the Auditor General highlighted that the recommended HF clinic community model was not fully implemented across the province, despite demonstrated benefit in several regions.<sup>82</sup> The major themes, which coalesced across the multiple stakeholders interviewed, were health system organization-related challenges, referral appropriateness and timeliness, variation in clinic characteristics, patient-related factors and the pandemic (Figure 3).

Consistent with quantitative surveys of HF clinics and reviews in the country,<sup>7,16</sup> the major challenges to an optimal continuum of care for HF patients appear to be the lack of regional coordination of care at the government level, the limited number of clinics and limited capacity of existing clinics, lack of organization, standardization and clarity on the purpose and specialization of clinics given the existing variation,<sup>7</sup> the lack of formal communication channels across the continuum and circle of care, as well as lack of guidance on who should or should not be referred to HF clinics. Consistent with the literature on access to other outpatient chronic disease care<sup>83,84</sup> as well as prospective Canadian studies<sup>49</sup> and reviews on HF clinic access

specifically,<sup>53</sup> patient-related barriers identified related to social determinants of health, their health status, transportation (parking cost, traffic, distance), time, and technology.

There were some conflicting viewpoints and needs expressed among stakeholders. For example, patients refused in-person visits for fear of contracting COVID-19 or could not come on-site because the informal carers accompanying them were not in compliance with COVID-related policies. However, based on types of diagnostic tests, length of time since seeing a patient or level of risk, providers often need to have in-person rather than virtual visits. There was also some tension between the need to reduce variation in HF clinic capacity and approach but also to match these to the population, particularly given the diversity in Ontario.

Many facilitators to improve HF care in the community and reduce the need for acute care were identified (Table 6). CorHealth-- which promotes the "spoke-hub-node" model<sup>85</sup> -- is an important mechanism to support coordination across the continuum of care and between HF clinics, to facilitate better care coordination, standardization, efficiency and patient-centeredness, even in the COVID-19 context. This model suggests that level of care and setting should be based on patient risk and complexity, from “spokes” for stable, low-risk patients to receive care in the community, to tertiary “nodes” where high-risk patients with complex needs receive care in an advanced cardiac hospital. There was an HF clinic network in the province, where the “node” level of the recommended “spoke-hub-node” model was in place, however it ceased due to insufficient support. The system needs connection to primary care “spokes” and “hubs” in a fully regional model, and that is explored in some of our forthcoming work. And again, given population and geographic diversity in the province, the standardized model should be resourced and implemented based on regional needs.

Standardized, evidence-based recommendations regarding who should be referred to HF clinics are also needed. The I-NEED-HELP<sup>86</sup> acronym from the American College of Cardiology Expert Consensus Decision Pathway for Optimization of HF Treatment is an example of a such recommendation for advanced patients; Canadian guidelines provide some direction as well (see Table 2 of <sup>16</sup>). Moreover, the COACH trial undertaken in the province is a promising model for the care continuum.<sup>87</sup> The intervention comprised a point-of-care algorithm which stratified HF patients based on risk of death, to support hospital discharge decisions, but importantly this was coupled with rapid follow-up in HF clinics for those discharged. Some interviewees were part of the trial, and greatly advocated for the model (Table 6), which would also improve referral appropriateness and timeliness. With results demonstrating significant 30-day reductions in mortality and morbidity with the rapid access care, implementation should be pursued. Finally, clinic staffing and funding policy should be re-visited, so they can be resourced to provide a full cadre of needed care in a patient-centred manner.

Results of this study have implications not only for policy, but also for future research. While many HF clinic access facilitators were identified, the expert panel perceives it would be premature to develop guidance until the viewpoint of those who refer patients to HF clinics, namely primary and acute HF care providers, are also sought, and until evidence regarding appropriate but also feasible HF clinic inclusion and exclusion criteria is undertaken (e.g., test the I-NEED-HELP acronym from American College of Cardiology Expert Consensus Decision Pathway for Optimization of HF treatment<sup>86</sup>). With this information, an expert panel could be convened to undertake a formal, evidence-based process to develop recommendations on improving the HF clinic system.

Caution is necessary when interpreting the results. First, representative generalizability is not established through qualitative research, so while purposive sampling was used and saturation was achieved, applicability to other provinces or healthcare systems cannot be known. And it should be noted that the patient population did not have rural representation and there were few HCP working at non-tertiary centres. Second, while face-to-face interviews are ideal, given the COVID-19 pandemic, interviews were performed via videoconference. However, one member of the research team notated non-verbal communication during each interview. Finally, the nature of the study design precludes causal conclusions.

In conclusion, this qualitative study gleaned the perspectives of PMs, HF clinics and patients regarding gaps in referral and access to HF clinics –gaps which impede optimal care quality and hence quantity of patient life-- in a public healthcare system. Main themes identified related to health system organization, referral appropriateness and timeliness, clinic-related factors, patient-related factors, as well as the COVID-19 pandemic. It is hoped these findings, congruent with quantitative and other local evidence, as well as the recent Auditor General's report, will spur consideration of care alignment with CorHealth Ontario's regional model of integrated care and the recent COACH trial findings. Resources must be provided and stakeholders brought together to standardize and integrate the HF care continuum, so that patients who need HF clinic care most will access and benefit from such care.

Figure 3: Five Major Themes on Access to Heart Function Clinics

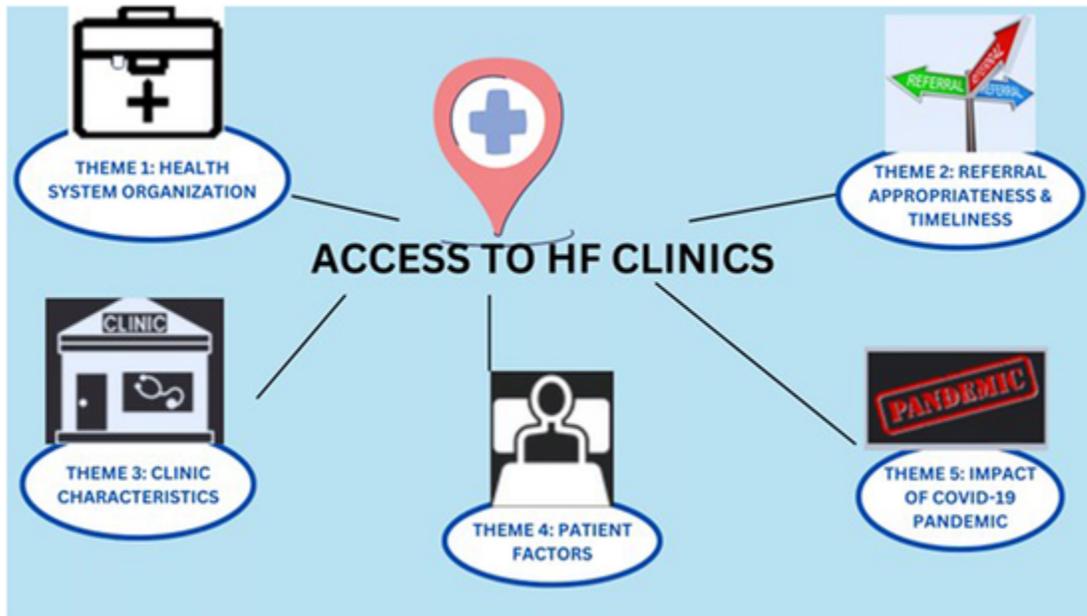


Figure legend: COVID-19, Coronavirus disease 2019; HF, Heart failure

Table 4: Characteristics of interview participants, by stakeholder group

	n (%) / median (range)
<i>Patients</i>	4 (23.52%)
Sex (n, % female)	2 (50.00%)
Age (years)	34 (20-65)
Geography / Residence	
Urban	3 (75.00%)
Other	1 (25.00%)
Duration living with HF (years)	5 (2-11)
Recent visit to emergency department for HF (n, % yes)	4 (100.00%)
<i>Heart Function Clinics</i>	7 (41.17%)
Profession	
Physician	6 (85.71%)
Nurse	1 (14.28%)
Years worked at clinic	16 (2-30)
Institutional Type	
Tertiary Center	5 (71.42%)
Other	2 (28.57%)
Number staff working	9 (7-30)
Annual patient volume / case load per clinic	800 (400-2200)
<i>Policymakers</i>	6 (35.29%)
Jurisdiction	
Provincial	1 (16.66%)
Regional or other	5 (83.33%)
Education	
Master's	5 (83.33%)
Doctorate	1 (16.66%)
Years working in cardiac care policy	11 (3-32)

HF, Heart failure.

Table 5: Exemplar Quotes by Sub-Theme

Theme (Sub-theme)	Quote (participant type, number)
<b>Health System Organization</b>	
Care continuity	<p>In short, the system in the province is poorly structured to manage HF patients. ...It was usually like eight weeks or 12 weeks or something like that, for the family doctors to follow-up... and the worst-case scenario was ... there was no follow-up. (PM4)</p> <p>Yeah, I do feel that, because these are the kind of, these are the same patients that keep coming into our Emerg. because they're not being properly managed, or they don't know where to go and so they don't have anywhere else to go [such as a clinic]. They come back to Emerg. (PM5)</p> <p>We have an established HF pathway that looks towards ensuring that patients have follow-up in our HF clinic within one to two weeks post-discharge.... Currently, we only see about half of the patients that we discharge with a diagnosis of HF. And we know that if we're not seeing the majority of them, the risk for them to be readmitted to the hospital due to a HF complication is much higher. (PM6)</p> <p>My cardiologist decided because, after almost nine years I'm stable, XX is much closer for us to go to. And I also see, my electrophysio cardiologist at XX and I also go to XX for my pacemaker defibrillator. So, I already go to XX for two different cardiology issues. Yeah, so she felt that I might as well go there for the HF clinic. But I haven't been accepted there yet, so I</p>

don't know. So, I was referred in October to XX regional health center and I didn't hear anything. (PT1)

So, ... on discharge summaries for example, there's a note that says 'refer to HF clinic'. And nobody's picked up the referral. (HFC1)

We have no streamlined way of working through, um, orders from a telephone perspective. So, I know a lot of other hospitals will work on titration of medications like Lasix and potassium and sometimes beta-blockers, depending on what patients are showing clinically on the outside. And a lot of that is just a call and they have to maintain parameters within a certain range for blood work, et cetera. And we don't really have a standardized way of doing that. And it's very physician-oriented... it puts a bit of a hitch in the plans of smooth transitions to the community, and they end up coming back fairly frequently for clinic visits that might have been avoided otherwise, and our population's not very mobile. (PM1).

The plan is basically for faster inpatient discharge and stronger community supports for patients with HF that are recognized as having HF and meeting certain eligibility criteria, um, to follow-up with that. ...It seems to be very physician dependent; Some patients we are seeing early enough that we can start them on medication, that we see an improvement in their EF, follow-up [echocardiograms], et cetera. And then the other patients we see, it's too many hands in the pot trying to change things; those people need to be seen more regularly by at least one clinic that can look after everything. (PM1)

	<p>So, we are looking for policies, like how do we enable and utilize Family Health Teams and how do we engage primary care and general practitioners so that they know enough, that they're knowledgeable enough to support their patient with HF so that they're not solely relying on a clinic. What's our role as a regional hospital to support the smaller hospitals in maximizing their efforts in supporting health for the patients? (PM2)</p> <p>We identified that the pathway for an HF patient wasn't clear, especially in the acute care setting and where they go. And what we identified is that even in the city of [xx] we had 16 different discharge destinations that a patient with HF could utilize post-discharge from an acute care hospital. (PM2)</p> <p>The government is focused on the 30-day readmission rate. If you think about it, if a patient's being discharged from hospital, but no one sees the patient, or many patients aren't seen within 30 days. And I often say if you don't see that patient until the 29th day post-discharge, you're not going to reduce 30-day readmission. So, there are huge challenges, uh, in the system as well. (PM4)</p> <p>In hospital at the time of discharge, they'll just put a discharge order for follow-up and HF clinic, and then that comes electronically to us. And then the other route is just like paper-based, like fax referrals. (HFC7)</p>
<p>Limited capacity/ volumes</p>	<p>HF clinics have capacity issues, you know, broadly... We're working through the hub-and-spoke model to be able to increase the capacity of</p>

some of the smaller hospitals ... and we're doing that through virtual clinics and through virtual visits with patients and families. (PM3)

One of the issues is capacity... I think we probably could be better at discharging patients from our HF clinic. If we go back to what I was talking about earlier about, you know, the goal to prevent readmissions, we're not able to see all patients after HF hospitalizations. And part of that is because often patients get stuck in their HF clinic. (HFC7)

The big one is lack of capacity in the community, which is big....There's not enough capacity to manage HF in the community and we can't do it all...These are people living in the community and if their HF could be managed -- especially when they're more stable --more often in the community to prevent exacerbations, then obviously we'd be able to see more patients coming in on the other end. (HFC3)

Yeah, I think there's some, there's some areas, there's certainly some regions that don't have access to any kind of clinic. They're being seen as part of a primary care office, um, practice. And when they run in to trouble, they'll refer them to other centers. But there's some areas that don't have a HF clinic in their community at all. (PM3)

But I think part of the challenge in terms of referrals is also discharging from the program. And that gets back to the, um, capacity of the system to look after the less complex, more stable HF patients. There's lack of comfort in doing that. And it's sort of a bottleneck really. (HFC3)

	<p>So, there's always this, um, tension between who is eligible for a HF clinic and who isn't. And it depends on volumes. (PM4)</p>
<p>Insufficient funding</p>	<p>There's no funding for a HF clinic right now. .... If a hospital sets up a HF clinic, they're doing it and pulling it out of their global budget or they've done some other gymnastics to take out some money. (PM4)</p> <p>You know, there are silos in funding in the system, and the patient suffers. Often the people who administer such programs see the world from their biased siloed perspectives, right? And so, um, the hospital has a budget and a lot of income from hospitals comes from surgeries and MRIs and procedures. HF is not a money-maker for anyone... So, to me, the way the system is funded does not reflect the needs of people with chronic disease. (HFC3)</p> <p>So, a patient comes into hospital, they might get admitted, and then they get discharged. They have no follow-up. They get put on some low dose of medications and you know, maybe we'll see them [in clinic] in six months, 'cause we get paid better for that. So, it all has to do with billing. (HFC4)</p> <p>For funding from an administrative perspective, a HF patient lives in the community. They generally have multiple other problems, and the way that funding is allocated on a regional basis is, is disproportionately hospital based. And so, from the funding perspective, if you want to increase capacity in the community, you know, an engineer or a business person</p>

will say, well, you shift money from acute care to the community-- which you can't do because they're funded through separate envelopes. (HFC3)

So as you are aware, the government doesn't pay for clinics. It's paid for by the hospitals, and the region...So this clinic here is run by the hospital. So there are very strict criteria because they're looking for a very specific goal. The goal was to decrease hospital readmissions... we're not seeing people who are otherwise the walking well, we're seeing the sick.. Yeah, that was the original reason. Otherwise, the hospital, was very interested, but they had no money. (HFC4)

But I think, the advantage of the hospital is that you know, there's a nurse and you know all those things that are kind of paid for by the hospital. So if we are to set up an HF clinic at our private clinic, where do we get the funding to support that? (HFC7)

If I put my hat on and said, okay, I'm going to sit as an administrator for the government. I could say, well, I don't know that I'm getting value for my money. Like you tell me, describe HF clinic. What's the structure of a HF clinic? And I would say, no one knows... We need to say that this is a HF clinic, so if you have X, Y, and Z and you have the population base, yes, then we will fund you to run a HF clinic. And I'm not talking about paying doctors, I'm talking about the infrastructure, which would include the administrative support, the nursing support. (PM4)

Because the patient population is large, and I think that's the key issue. So, you define what is a heart failure clinic, what are the components of a heart

	<p>failure clinic and what are the goals of the heart failure clinic and then you fund it appropriately...It doesn't have to be in the university center, it could be anywhere, but you need to meet certain criteria and they would fund that. The Ministry is not interested in anything that's open-ended; They want very clear, defined things. (HFC4)</p>
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**Referral Appropriateness and Timeliness**

<p>Variation in clinic referral criteria / scope</p>	<p>And then I go over each of the referrals with their supporting data to say whether or not they should be seen by us. A lot of times I feel that and say they should at least be seen by a cardiologist first before seeing us. So, we are a second step sort of clinic... Obviously, if they're very sick, we'll see them without having a cardiologist at first. But we prefer them seeing a cardiologist; Have at least follow-up and tried to do some initial HF therapies. (HFC5)</p> <p>Well, there's not enough capacity to manage HF in the community and we can't do it all. And so, you know, that's partly why the [referral] criteria are a bit stricter. (HFC3)</p> <p>I think the idea of let's open up the doors, everybody, it's very ideal but you won't be able to cope with them and you won't be able to discern between who's sick and not. (HFC4)</p> <p>But we, as far as acuity goes in area and all of that, we don't put a limit on where we're receiving patients from... And we've had patients that have come from other clinics that no longer want to be followed there and would</p>
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rather come to us. So it's sort of built around preference in that perspective (PM1)

Well, I think because we're the largest tertiary clinic in the [XX], well, we are the only tertiary center, it's part of our mandate to be accessible. (PM2)

So if you don't treat people then it won't be very long before they meet the criteria, right? A lot of patients, we do a very good job with them because a lot of patients were under-treated, and you know, there's exceptions to the rule. (HFC4)

And we see patients primarily on just one day a week, which is a little bit of a limitation. And we don't really turn away anybody, although the patients primarily come from inpatient... But we would never turn any family doctor, any referral from anywhere away. (PM1)

I mean, uh, we don't [have referral criteria]. As I said, we don't really use checklists or anything... I mean, I think it's just sort of like our gut feeling that this patient could use some more support [such as] what we can offer in the clinic. (HFC7)

If you say, well, I'll take them in after one hospitalization. In a year, you're getting less sick individuals, the volume goes up. But, again, if you say, okay, we will take people into the HF clinic who have had two hospitalizations within the last year, um, you realize that you're getting sicker patients, but you're ignoring all the less-sick patients. So, there's always this trade-off. I think the HF clinics are overwhelmed right now. So, to say we're all going to open up the tap and pour more patients into

	<p>them. All we're going to do is end up generating longer wait lists. In fact in [xx] we've re-evaluated our inclusion criteria and tightened it up. (PM4)</p> <p>And because these are high-intensity HF patients, so we have a very strict criteria for coming to our clinic. (HFC5)</p> <p>So each clinic is probably a bit different or, you know, more lenient vs more restrictive based on their capacity or things like that. But I don't think that we're too strict in terms of, you know, who gets to get into the clinic. (HFC7)</p> <p>We're missing a good chunk of the population by not seeing the cardiac-oncology population; we have to refer those patients elsewhere... The ones that have had HF just cause they're on chemo. I think a lot of the, the issue is the role of the clinic isn't understood across the board by all hospitalists, and about who should access right away. (PM1)</p>
<p>Referral appropriateness</p>	<p>Unfortunately, education is one of them, like these inappropriate referrals, it's because the referring physician is not educated exactly on what heart failure is. (HFC5)</p> <p>So in terms of meeting criteria, they generally do sort of. I guess the question is, are all patients who should be referred, referred? And I don't think so. Just so you can avoid the re-admissions that obviously plague HF patients. Mainly a lot of frail, older people tend to be not seen as worthy. (HFC3)</p> <p>I think if somebody's being referred and the cardiologist feels that that they're not needed in the clinic, they would probably have a conversation</p>

with the referring physician. Sometimes they'll just say they want a plan for medication up-titration, so they can ask for some very specific things. But we would always be back in touch with the referring physician if we thought for some reason that, that the patient was inappropriate. (PM3)

Um, because there are patients who are low-risk and there are patients who are high-risk. And the question was, can we improve the triaging of those patients? (HFC2)

We can speculate, if you look at the literature, that often a general practitioner does not actually recognize patients who actually have HF and would benefit from sub-specialty HF care, whether that be in the community or tertiary. (HFC2)

As far as the family doctor referral process, I think it's just, if they recognize it and they see it, they'll refer. There's nothing standardized....Um, but there's no standardization of where patients are sent. (PM1)

So we do get referrals that are not 'classic' HF. So I'm not sure if you would call them inappropriate referrals, but we do see patients that are sort of outside the realm of general HF.... I think all clinics feel that there's general HF that is not being referred. So, a lot of us do see that. But I'm not really quite sure how to, uh, substantiate that. (HFC2)

Well, all referrals are screened as they come in. And then they are prioritized based on the referring clinicians' indication. We can redistribute, so if a patient is referred that does not appear to be a HF

	<p>patient, we may redistribute that, so that we don't use the HF clinic resources, but they're still seen. (HFC2)</p> <p>We've got a lot of patients that end up there that have exacerbated COPD but they haven't had a BNP, and they get referred to us and it's not an appropriate referral. (PM1)</p> <p>Well, the Nurse-Practitioner will help ...redirecting those patients to the appropriate environment. (PM6)</p> <p>So depending on what the patient presentation is, I either redirect the referral to our general cardiology clinic that's outside of the hospital or if they've been seen by a cardiologist, which is sometimes the case, I'd redirect back to the cardiologists and say you can follow-up on this concern. Or if it's completely inappropriate, we just sent back to the GP or whoever it was that referred, and say 'no', that this is inappropriate; I would say less than 10% we just send back without some sort of action. We actually do the work to re-refer them back to other clinics. (HFC5)</p>
<p>Timeliness / efficiency</p>	<p>I think a lot of the issue is the role of the clinic isn't understood across the board by all hospitalists, and about who should access [one] right away.</p> <p>So, we have some physicians that are great at referring from the inpatient side and others where we see patients repeatedly get admitted before it's finally made. So, it's really variable because I think a lot of it is very physician dependent, unfortunately. (PM1)</p>

With the ones that are referred, are they referred on time? Like is it at the right time? Sometimes, no. (HFC3)

Yeah, it seems to be the limitation is in terms of how soon we can see them. Um, just because we're built around just the two physicians that have limited time in clinic. So that's the limitation. (PM1)

Sure. I mean these clinics are very busy for sure. And um, you know, we do watch, I mean you have to watch how long the gap in time is between patient visits and make sure it's timely. (PM3)

A lot of it is just the support that the HF clinic can provide for the inpatient end. And about how fast they can safely discharge and how fast we can triage patients, 'cause there's always a shortage of spots. (PM1)

In terms of records, for a lot of these referrals we have to dig through multiple different systems, as I don't think they use [the same electronic health system]. So if we need notes, we have to figure out who the clinician is and ask their office directly. So it's a lot of time to process these referrals, because you wanna know all the information before you spend the time to sit down and talk with them in-person and whether or not it's appropriate. So, our nurses have to dig a lot because yeah, because the clerical staff might not know whether the patient is relevant or not. So, then it takes the nurses to go hunt and look. And so more time and energy.

(HFC5)

When I talk to physicians about why they choose to send to us, a lot of it is wait time; So, if they see shorter wait times elsewhere, they'll send patients elsewhere. (PM1)

We can accept every patient, but the waitlist is long. I would say we have a fairly good compliment right now of general cardiologists. It's just because of the demand, the wait period is as long. (PM2)

I feel like the funding and the wait time for HF clinic might need to improve, like, uh, I didn't wait quite long to go into clinic. I feel like either solving that problem with an intermediate solution or having quicker access to clinic is really important..... And you know that physical touch point is super, super important... Um, but without the occasional touch points, it felt very long. ... I got pretty lost most of the time. (PT2)

It can extend out as far as a month, sometimes up to six weeks if it's really bad. (PM1)

So for example, if we found like the readmissions were up in the hospital part, we might take a look at the clinic and see whether or not people are getting timely access to clinic resources, et cetera. (PM3)

It's really just, uh, trying to see people. And we really do try to see people no longer than one month waiting time. And, you know, we originally started at two weeks, which became a little bit impossible. But we're pretty well on to one month, and that's again because we're very strict with the criteria and stick to those criteria. (HFC4)

	<p>It's variable depending on what the on-call schedule is for those those physicians. So for instance, March is a really bad month for them. That might look more like a three to four-week interval, but we have other periods of time where they can be seen within seven to 14 days. So, I would say if you want to put an average on it, anywhere between two to three weeks, but it can extend out as far as a month, sometimes up to six weeks if it's really bad. (PM1)</p> <p>...but when it comes from the community though, they'll ask 'what's your wait time for seeing this patient next'? And if we're shorter than the next place they were going to refer to, then they'll refer to us, and if we're too long then they'll refer them downtown. (PM1)</p> <p>Well there's a big fear of the wait time in terms of seeing patients. (PM1)</p>
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**Clinic Characteristics**

<p>Clinic-to-clinic service variation</p>	<p>I think that it's very heterogeneous. One of our priorities is to be accessible. So it does mean that we have a bit of a reputation for also seeing challenging or unusual or strange cases as well. (HFC2)</p> <p>So this HF clinic at [XX] was designed to be a discharge HF clinic, meaning it's specifically for patients who have just been discharged from hospital or have gone to the emergency room because of what was felt to be HF as the primary diagnosis. So that's the intended population. We see these patients for three to six months, during which time our goal is to optimize their HF, medical therapy, sort out the etiology of their HF. The intention of this clinic was specifically to see patients who have just been</p>
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	<p>discharged from hospital. That's its mandate. (HFC6) We are not sophisticated like Toronto, but we have different sorts of clinics..... So some of those patients may go to the pre-transplant clinic. (HFC4)</p> <p>And there seems to be a lot of variability in terms of the palliative component. We right now link with [palliative clinic]. I know the central LHIN has got a strong link with their clinical nurse consultants for their hospice and palliative care. They seem to be bigger centers. (PM1)</p> <p>As i said, we all have specific expertise. So we have expertise in hemodynamic assessment and cardiac biopsy and autonomic physiology. So those referrals are sometimes from out-of-province as a result. (HFC2)</p> <p>They have like a dedicated slot where they see OTN patients through basically webcam interviews that are linked with nursing homes, and they'll have this beautiful setup where it's the nurse-practitioner in clinic seeing the patient through webcam; a dedicated time every week. (PM1)</p>
<p>Variation in composition and number of HCPs on clinic team</p>	<p>A lot of concerns because we ended up where our clinic is staffed with two nurses right now. We were staffed with three, and two physicians. (PM1)</p> <p>The current model is it's one afternoon a week on Mondays and it's 10 patients in that clinic on average; three to four new and six follow-ups. That's kind of the balance... it's too much, to be honest. HF patients are very heavy. No, not many people I know do a whole 8:00 AM to 4:00 PM clinic of HF. At least not in academic centers. Nobody would. It's too much. Most clinics are either half a day in the morning or half a day in the afternoon. (HFC6)</p>

	<p>The second group would be complex patients, with other medical problems that might contribute to their HF, for example, renal failure. As I said, we do have a nephrologist and it's, uh, a patient on dialysis, uh, some of the cancers. So, we work with the lymphoma group, multiple myeloma group. So those sorts of things versus the very specific other illnesses, which HF is a part of. (HFC4)</p>
<p><b>Patient Factors</b></p>	
<p>Comorbidity/frailty</p>	<p>Some of these elderly patients with mobility issues who are, you know, mostly, you know, home-bound. It's just difficult for them to come to appointments. (HFC7)</p> <p>We had a patient who was quite elderly, over 90, who was not mobile...unable to come. (HFC6)</p> <p>The common reasons they're unable to attend, usually the commonest reason, is that they are too sick to attend. Virtually all of the patients we saw were high-risk. And they were high-risk because of age and frailty... So, we do seem to actually embrace the frail patients. (HFC2)</p>
<p>Socioeconomic status / social determinants of health</p>	<p>Yeah, parking costs are definitely kind of painful... it must be pretty difficult for other people financially to even make these trips to the hospital. (PT2)</p> <p>But when I have to go down to the hospital, I don't have a car, so I have to Uber. So it's expensive and no one's reimbursing me for that. And I'm not working right now. So it's kind of a pain. (PT3)</p>

	<p>And you know, there's algorithms for prescribing. So why can't we have an algorithm for seeing a patient? But the thing is patients are all different, and that gets back to their comorbidities, socioeconomic considerations as well as their disease. (HFC3)</p>
<p>Logistical barriers (e.g., transportation, traffic, distance)</p>	<p>Like I can wake up, my parents have to wake up pretty early and we have to take the day off or something. And then, you know, me being a whole day out of it for the appointment downtown. (PT2)</p> <p>The fact that they need to, you know, get someone to transport them over. So that definitely makes them miss appointments a lot of times. Getting the message to them... sometimes the phones aren't working. We're kinda a little archaic that we still sometimes mail out our appointment times. But again it you know they don't get the mail or they don't check it so they don't show up the last month. (HFC5)</p> <p>We're notorious; our cardiologists take a while to see patients. Um, so sometimes between seeing the nursing staff and having their full assessment and the cardiologists, they are waiting for like an hour or two hours. A lot of the patients that really hate the wait time just refuse to come back because of that. So it's not to do with clinical status at all. It's just the wait time. It doesn't work for them. (PM1)</p> <p>We have just in the last year have seen an explosion in our referrals and in our heart function census. So we, we have up in over 600 rostered patients in the clinic now. We would like to have more of a regional program where we have satellite clinics within the area because our LHIN is quite large.</p>

	<p>We have quite a long distance in between our sites. And so it makes it difficult for patients to access care. So we are trying to figure out ways to be able to reach patients in further distances. (PM5)</p> <p>..was how could we utilize technology, remote monitoring software so that patients that are living in [XXX] for example, don't have to travel into [YYY].... From what we're hearing, the patients would rather be at home. (PM2)</p> <p>So many patients don't want to come to a downtown clinic. Just the issues that come along with being at a downtown clinic such as parking, and just access. So really location would be the major issue that I think would reduce not only referral, but that patients may actually request referral elsewhere closer to home. (HFC2)</p> <p>It was just the distance to [xx] and the traffic. Sometimes if there was some issue on the 401 highway or whatever, we would be late for an appointment. So we would leave quite early in the morning. If we had a nine o'clock appointment, we would leave just after five in the morning. (PT1)</p>
<p>Affinity to specific providers</p>	<p>But a lot of people do wanna be followed by the same people who took care of them right after their hospitalization. So that's where I foresee a bottleneck... not every patient wants, you know, it's very hard to discharge patients. And part of that is because, in my experience, during the pandemic, many of them want to hold on to specialist care. (HFC6)</p>

	<p>And a lot of them will make specific requests to be seen solely by us. (PM1)</p> <p>Um, our hospitalist almost always works with the family doctors in the community. A lot of our patients prefer to see her over there. She's like hyper-involved with patient care and they really love that. Um, so a lot of times they'll see her instead of the family doctor routinely. (PM1)</p> <p>And part of it I think is that they just sort of like the attention and care that they get. I mean, they have a nurses cell phone number that they can call 24/7, essentially. And so some patients, you know, do become quite dependent on the service that they get and their HF clinic and when we try to discharge them to our general cardiology clinic they resist that. (HFC7)</p> <p>We've had patients that have come from other clinics that no longer want to be followed there and would rather come to us. So, it's sort of built around preference in that perspective. (PM1)</p>
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**Impact of COVID-19 Pandemic**

<p>Transition to online delivery modalities</p>	<p>I'm hopeful that we're going to see more. It is a little more challenging with our HF population as they are a much older demographic. However, quite often those patients, their children are involved in their visits, and we see that as helping to facilitate that move towards virtual clinic visits. And actually we were getting sort of a trial by fire right now with, with the whole COVID situation. You know, today's a perfect example. We're</p>
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	<p>seeing a few urgent patients today in our clinic this morning, but the cardiologist is conducting the rest of his visits over the phone. (PM6)</p> <p>Now we did move a lot more to telephone or divert some of the follow-ups. (HFC5)</p> <p>We kind of functioned pretty much throughout all of COVID with very minimal virtual visits because of the type of patients we take care of; because I can't talk to somebody on the phone until I really understand what their volume status is. (HFC6)</p> <p>The thing that I know has come up recently is physician compensation through the use of, um, technology or telemedicine. There's some restrictions that Ontario is starting to put on through OHIP for the way the physicians get funded (PM2)</p> <p>We currently run a virtual clinic, um, for about, I'd say 20% of our existing patient population. So, if they have a clinic appointment that won't involve any diagnostic imaging or lab tests, they have their appointments set-up over OTN as long as they are able to carry that out. (PM6)</p> <p>I think we got a lot more referrals where they should have been seen by someone else first... The family physician never even assessed this patient in-person, and then was just sent to us. (HFC5)</p>
<p>Patient refusal of in-person care</p>	<p>I think from a practical level, it did get a bit difficult in terms patients refusing to come in because they were worried about COVID, unfortunately then end up in the hospital... They refused to come see us,</p>

	<p>we couldn't do anything... It was harder because we couldn't communicate with the care partner because the care partner refused vaccination. (HFC5)</p> <p>I think like COVID has, I mean particularly you know providing HF-based care in hospital-based clinics, I think COVID definitely threw a wrench in that... a lot of the patients were, like, terrified to come into hospital. (HFC7)</p> <p>With COVID, like a lot of reluctance from the patient's standpoint and some of that has lingered as well... Yes, they were afraid of catching COVID. (HFC7)</p>
<p>Loss to follow-up</p>	<p>But because of COVID, I at the moment don't have a cardiologist. I've been discharged from one hospital and the other clinic is not taking anybody... I called the HF clinic, and I asked and they said don't expect to hear from the HF clinic for months because of COVID. So I don't even know if I've been accepted... I feel like I'm in limbo at the moment. It's very, it's stressful in that sense. (PT1)</p> <p>We were looking into the fact that we miss about 50% of our patients, but at the same token as well, um, the question is, okay, if we saw all of a sudden had all of those 50% coming in for appointments, how would we manage that because it would quickly become unmanageable. So part of the issue with that is our workflows are slowed down due to COVID. (PM6)</p>

BNP, Brain Natriuretic Peptide; COPD, Chronic Obstructive Pulmonary Diseases; COVID, Coronavirus Disease; EF, Ejection Fraction; Emerg., Emergency department; PT, patient; PM, policymaker; HF, Heart Failure; HFC, Heart Function Clinic; HCP, Health Care Professional; LHIN; Local Health Integration Network (i.e., regional health authority); MRI, Magnetic

Resonance Imaging; MD, Medical Doctor; NP, Nurse-practitioner; OHIP, Ontario Health Insurance Planning; OTN, Ontario Tele-health Network;

Table 6: Facilitators to Referral and Access to HF clinics as perceived by stakeholder groups

THEME	FACILITATOR
Health System Organization	Department / committee meetings across continuum of care, to track patient flow and timeliness / wait for 1 <sup>st</sup> HF clinic visit
	Triage tool for the emergency department
	Facilitating relationship between tertiary and community HF clinics, to extend capability of community clinics. E.g., <ul style="list-style-type: none"> <li>• Spoke – hub – node CorHealth Ontario policy§</li> <li>• Augmenting capacity of Family/Ontario Health Teams</li> <li>• Leverage cardiac rehabilitation programs in communities without HF clinics</li> </ul>
	Electronic referral, leveraging electronic medical records
	Training/education of emergency physicians regarding clinic availability and services
	Linkage with nursing homes
Referral Appropriateness and Timeliness	A one-stop online resource for referring physicians to characterize HF severity and act accordingly e.g., <ul style="list-style-type: none"> <li>• COACH trial<sup>88</sup></li> <li>• CorHealth Ontario’s HF Care Support tool‡</li> </ul>
	Clear referral criteria (e.g., I-NEED-HELP acronym from American College of Cardiology Expert Consensus Decision Pathway for Optimization of HF Treatment <sup>89</sup> )
	Marketing, communicating referral criteria
	Rapid access clinics <sup>88</sup>
	Foster relationship with diagnostics departments
	Intra-clinic triage

Clinic Factors	Clinic relationship with emergency and inpatient departments at hospital, so can support shorter length of stay, which is hospital goal for reimbursement reasons
	Linkage with referring providers and other providers in circle of care (e.g., give them information they need to manage patient [while ensuring good communication about medication changes], etc.)
	Linking with other HF patient care resources (e.g., palliative, community / home care [weighs, blood pressure assessment])
	Protocol for non-physician/ nurse to handle patient symptoms / medication changes by phone, so clinic has capacity for new patients
	Electronic dashboard tracking referrals, current patient load, and discharge eligibility
Patient Factors	Protocol for non-physician/ nurse to handle patient symptoms / medication changes by phone so patients do not need to travel in
	Offering virtual appointments
	Patient-oriented discharge summary
	Appointment reminders (interactive voice response)
	Engaging family supports, informal caregivers

HF, Heart failure; HFC, Heart function clinic

[§https://www.corhealthontario.ca/resources-for-healthcare-planners-&-providers/integrating-heart-failure-care/The-Spoke-Hub-Node-Model-of-Heart-Failure-Care](https://www.corhealthontario.ca/resources-for-healthcare-planners-&-providers/integrating-heart-failure-care/The-Spoke-Hub-Node-Model-of-Heart-Failure-Care)

[#https://www.corhealthontario.ca/resources-for-healthcare-planners-&-providers/integrating-heart-failure-care/Overview](https://www.corhealthontario.ca/resources-for-healthcare-planners-&-providers/integrating-heart-failure-care/Overview)

## **CHAPTER THREE**

PAPER TWO: Factors Affecting Healthcare Provider Referral to Heart Function Clinics: A  
Mixed-Methods Study.

CERTIFICATE OF AUTHENTICATION

**Mamataz T**, Lee DS, Turk-Adawi K, Hajaj A, Code J, Grace SL. Factors Affecting Healthcare Provider Referral to Heart Function Clinics: A Mixed-Methods Study. J Cardiovasc Nurs. 2024 Jan-Feb 01;39(1):18-30. doi: 10.1097/JCN.0000000000001029.

The candidate assisted in securing institutional ethics approval. For the qualitative portion, she reached out the potential interviewees by email, scheduled interviews after securing informed consent and then conducted the interviews, videorecording and taking notes. She also cleaned the transcripts and undertook data analyses in NVivo. The candidate also undertook quantitative data acquisition by sending the REDCap survey to potential participants and tracked response rates. She performed the data analysis in SPSS. Finally, the candidate prepared the first draft of the manuscript, including the themes with corresponding quotes and quantitative data analysis. She incorporated co-authors input in subsequent manuscript versions and responded to journal peer reviewer revisions.



Signature: \_\_\_\_\_ Date: Jan 04, 2025

Taslima Mamataz



Signature: \_\_\_\_\_ Date: Jan 04, 2025

Sherry L. Grace

## ABSTRACT

**Background:** Heart failure (HF) care providers are gatekeepers for patients to appropriately access life-saving HF clinics.

**Objective:** To investigate referring providers' perceptions regarding referral to HF clinics, including the impact of provider specialty and the coronavirus disease pandemic.

**Methods:** An exploratory, sequential design was used in this mixed-methods study. For the qualitative stage, semi-structured interviews were performed with a purposive sample of HF providers eligible to refer (e.g., nurse-practitioners, cardiologists, internists, primary care and emergency medicine physicians) in Ontario. Interviews were conducted via Teams. Transcripts were analyzed concurrently by two researchers independently using NVivo, using a deductive-thematic approach. Then a cross-sectional survey of similar providers across Canada was undertaken via Research Electronic Data Capture (REDCap), using an adapted version of the Provider Attitudes Toward Cardiac Rehabilitation and Referral (PACRR) scale.

**Results:** Saturation was achieved upon interviewing seven providers. Four themes arose: knowledge about clinics and their characteristics, providers' clinical expertise, communication and relationship with their patients, as well as clinic referral process and care continuity. Seventy-three providers completed the survey. The major negative factors affecting referral were: skepticism regarding clinic benefit ( $4.1 \pm 0.9/5$ ), a bad patient experience and believing they are better equipped to manage the patient (both 3.9). Cardiologists more strongly endorsed clarity of referral criteria, referral as normative and within-practice referral supports as supporting appropriate referral vs. other professionals ( $p < .02$ ), among other differences. One-third ( $n=13$ ) reported the pandemic impacted their referral practices (e.g., limits to in-person care, patient concerns).

**Conclusion:** While there are some legitimate barriers to appropriate clinic referral, greater provider education and support could facilitate optimal patient access.

## 1 INTRODUCTION

Heart failure (HF) burden is rising exponentially globally.<sup>64</sup> It is associated with high mortality and morbidity, resulting in significant health care costs.<sup>2</sup> While there is no ‘cure’ for HF, early diagnosis and evidence-based care<sup>12</sup> can increase longevity and improve quality of life.

However, care recommendations are complex, often requiring subspecialist physicians to support optimal guideline-directed pharmacotherapy, patient self-management across multiple health behaviors as well as candidacy assessment for device therapy, among other care.<sup>90</sup> For this reason, guidelines recommend high-risk HF patients be referred to HF clinics.<sup>8,12,16</sup> While there is wide variation, HF clinics are outpatient sub-specialty centers offering rapid care access to prevent acute decompensation, and are staffed by a multidisciplinary team.<sup>24</sup> Robust evidence demonstrates that use of HF clinics is associated with significantly lower mortality and morbidity, and that they are cost-effective.<sup>11,72</sup> Despite these benefits, utilization is low (~20%<sup>15,28</sup>) and often inequitable.<sup>50,91</sup> For example, older, female patients and those with preserved ejection fraction less often receive clinic care. Thus, it is imperative that physicians and other advanced practice providers caring for patients with HF refer “appropriate”,<sup>12,16</sup> patients to these clinics in a timely manner to optimize health outcomes. Given the need to balance provision of the appropriate level of specialist care and cost efficiency, guidelines generally recommend patients with an ejection fraction  $\leq 35\%$ , New York Heart Association class III/IV, end-organ dysfunction, HF-related hospitalizations and/or issues related to guideline-directed medical therapy be referred, among other criteria.<sup>13</sup>

Although generalists and specialists play a key clinic referral gatekeeping role, there has been no quantitative study investigating factors affecting provider referral practices to our knowledge.<sup>16,53,92</sup> Interviews with policymakers, clinics and patients suggest limited capacity and

hence long wait times, as well as variation and lack of clarity in clinic-specific inclusion criteria are paramount. Moreover, some providers who should refer HF patients have limited HF diagnostic and care knowledge impacting referral, and care-related barriers and preferences patients convey to their referring providers (including related to the coronavirus disease [COVID-19] pandemic) are influential as well.<sup>92</sup> Research in the area of the more general outpatient chronic disease management programs of cardiac rehabilitation suggest there are some legitimate provider challenges to referral.<sup>93</sup> and that factors impacting referral practices can vary by specialty.<sup>94</sup> Therefore, the aims of this study were to investigate the factors affecting healthcare provider referral to HF clinics, how this might differ by provider specialty, and was impacted by the COVID-19 pandemic.

## 2 METHODS

The study was approved by the institutional review boards of University Health Network (#19-6171) and York University, Toronto, Canada. All participants provided informed consent electronically (Appendix H). An eight-member expert panel was convened, comprised of a representative of an HF patient organization, an HF administrator, HF physician sub-specialists, an HF clinic provider, members of leading HF committees in the country, among others. Panelists supported development of the research questions, methods and interpretation of results.

Given the novelty of this work, a mixed-methods study was undertaken, using an exploratory, sequential design.<sup>95</sup> In the first stage of this study, semi-structured interviews of providers who treat patients with HF and are eligible to refer to HF clinics were performed, in order to understand their perceptions of factors affecting their referral to HF clinics. These results were used to inform the second stage of quantitative data collection, in which providers meeting the same criteria were surveyed regarding their perceptions and attitudes in order to

understand how common these factors were and how they related to referral decisions (case scenarios).

The methods were integrated by means of merging, such that results of both stages were brought together for analysis contiguously. Interpretation of the integrated results was performed narratively, including consideration of fit of the results from the two stages<sup>95</sup> as well as with available literature and input from the Expert Panel.

## *2.1. Qualitative Stage*

### *2.1.1. Setting and Participants*

This phase of the study was conducted in Ontario. The healthcare system in Canada is administered provincially, so this ensured consistency in health system factors to enable in-depth investigation. HF clinic care is covered through government funding in Canada, although there are insufficient clinics, and those that exist are under-resourced.<sup>7</sup>

Ontario primary care and emergency medicine physicians, internists, cardiologists and nurse-practitioners who can make HF clinic referrals<sup>7</sup> were considered eligible for participation. Providers who did not treat patients with HF were excluded. Provider email addresses were purchased from a private company, by specialty (TargetNXT). We also searched faculty directories at medical schools in Ontario for addresses to email. To support purposive-sampling, emails were randomly selected across the specialties, with consideration of provider sex and region where email addresses conveyed such information. Selected providers were invited by email for qualitative interviews (Appendix F). As interviews progressed, Expert Panel members personally contacted potential interviewees with unrepresented characteristics to ensure diverse representation of input. Sample size was determined based on saturation of themes.

### *2.1.2. Procedure*

A semi-structured interview guide was developed to assess the views of referring providers regarding access to HF clinics (Appendix B). It was informed by our previous literature reviews,<sup>16,53</sup> and input from the Expert Panel. It was pilot-tested prior to study initiation. Items related to the COVID-19 pandemic were added later in the study.

The interview guide was provided to consenting providers in advance, and shared on screen during interviews. The individual interviews were performed from February to June 2020 and then halted due to pandemic; they resumed in July through December 2022. The interviews were performed via Microsoft Teams online, due to the wide geographic range of the province and COVID-19. The interviews were conducted by a senior member of the team, while a trainee observed to take notes and record non-verbal communication. Cameras of all parties were on for the duration of the approximately 30-minute interviews, and video-recorded with live auto-transcription; all participants also consented to video-recording.

### *2.1.3. Data Analysis*

Transcripts were cleaned to be verbatim (i.e., correcting any errors from auto-transcription against video recording) and anonymized. NVivo (version 12) software was then used for data organization and coding, concurrently with interviews. A deductive-thematic approach was used for analysis, as outlined by Crabtree and Miller.<sup>96</sup>

To minimize bias, two researchers coded independently first, and then discussed the results. When no new information was emerging, data saturation was considered achieved.

To ensure credibility, themes with sub-themes were then shared with the Expert Panel to inquire whether they resonated and requesting any input.<sup>97</sup> Final consensus on the themes was reached upon discussion with the senior author.

## *2.2. Quantitative Stage*

### *2.2.1. Design and procedure*

A cross-sectional survey (Appendix C) was administered online through REDcap (Research Electronic Data Capture) to health care providers eligible to refer to HF clinics across Canada. To optimize response rate, non-responders were re-sent the brief survey a maximum of 3 times, the third time often by a member of the Expert Panel. The survey was administered between March 2020 and April 2020, then from May 2022 to December 2022; recruitment was paused in the interim due to COVID-19. It was prefaced by an online consent form.

### *2.2.2. Participants*

According to recent Canadian estimates, there are 38,013 family physicians, 1,011 emergency medicine doctors<sup>98</sup> and 10,484 internal medicine specialists (some of whom treat patients with HF), including 1,485 cardiologists practicing in Canada.<sup>99</sup> In addition, there are 459,005 regulated nurse-practitioners working in Canada, although the number in cardiology specifically is not known.<sup>100</sup>

Healthcare providers (i.e., family and emergency room physicians, internists, cardiologists and nurse-practitioners) working in any setting (e.g., inpatient, outpatient) across Canada treating patients with HF were included. As outlined above, email addresses were purchased from TargetNXT. Overall, 2325 email addresses were acquired: 750 cardiologists (academic and non; all available emails), 200 family physicians, 200 emergency medicine physicians, 200 internists (subspecialty unknown) and 435 nurse-practitioners (although specialty was not known; all available emails). In addition, faculty directories of relevant departments at medical schools in Canada were searched for email addresses to optimize generalizability.

### 2.2.3. Measures

The first part of the survey consisted of investigator-generated questions querying participant's sociodemographic and occupational characteristics (Appendix C). Next were 35 items assessing participant's perspectives regarding referral to HF clinics. The survey was developed based on our Provider Attitudes Toward Cardiac Rehabilitation Referral (PACRR) scale,<sup>93</sup> our previous reviews in the area<sup>16,53</sup> and with input from members of the Expert Panel. Response options on a 5-point Likert-type scale ranged from 1 'strongly disagree' to 5 'strongly agree', or not applicable. Some items represented 'valid' reasons why a provider may not refer (i.e., based on local clinical practice guidelines).<sup>12</sup> Other items were reverse-worded to reduce acquiescence bias; these were reverse-coded to facilitate interpretation. Means of the (a) positive perception items, (b) valid referral barriers, and (c) negative attitude or perceptions were averaged to create a summary score.

There were two case scenarios in the survey (e.g., older female with HF with preserved ejection fraction, male with medication issues; see Appendix C for details), developed with input of the Expert Panel. Providers were asked whether they would refer the hypothetical patient to an HF clinic (yes/no) and then to provide a description of why or why not (open-ended).

Finally, questions related to the impact of COVID-19 on clinic referral practices were added in 2022. Most items had forced-choice response options, and skip-logic was used to obtain more detail where applicable.

### 2.2.4. Statistical Analysis

IBM SPSS version 28 was used for quantitative analysis. All initiated surveys with any data were included. The number of responses for each question varied due to missing data (e.g., use of skip logic, COVID-19 items only administered after the pandemic); for descriptive

analyses, percentages were computed with the denominator being the number of responses for a specific item. Open-ended responses were coded using content analysis.<sup>101</sup>

Given the attitudinal items were not normally distributed, Wilcoxon rank sum tests were performed to test the association of the attitudes and perceptions with provider specialty. A p-value <0.05 indicated significance, except when analyzing association with individual Likert items where a more conservative cut-off of 0.02 was used to minimize the potential of inflated error.

### 3 RESULTS

#### *3.1. Qualitative Results*

Ultimately, seven providers participated (6 post-pandemic). Their characteristics are presented in Table 7. Four main themes were identified, as illustrated in Figure 4. Exemplary quotes corresponding to associated sub-themes are shown in Table 8.

The first theme pertained to referring clinician knowledge about HF clinics and their characteristics. Sub-themes concerned: (a) knowledge of benefits of clinic use by patients; (b) knowledge regarding where the clinics are located (including those proximate to patient's homes) and their corresponding wait times (to ensure patient's can access care within a timeframe commensurate to clinical need); (c) knowledge of clinic-specific inclusion and exclusion criteria and referral process (e.g., test results needed, requirement of a specialist); and (d) having two-way communication with clinics to facilitate this awareness.

The second main theme pertained to the referring healthcare provider's HF expertise. Sub-themes were two-fold: their ability to identify and diagnose HF (so they can identify patients to refer), and their comfort in complex HF patient care. This included their clinical knowledge about HF medication titration, as well as device and transplant candidacy for example. Some

providers were comfortable managing patients on their own, while others relied on the HF clinics for this expertise.

The third main theme concerned the nature of their relationship with the patient, including their communication. Sub-themes pertained to: (a) perceived patient willingness to attend HF clinic appointments, considering also their potential barriers to attending; and (b) the impact of the COVID-19 pandemic on patient-provider communication.

The final theme related to making the HF clinic referral and care continuity. With regard to the former, logistical issues such as who is making the referral (and any support gathering needed information for example), mode of referral transmission (e.g., fax, electronic), and having the test results to send were paramount. Knowledge of clinical practice guideline recommendations regarding referral was also key. With regard to the latter, respondents spoke about the need to track receipt of patient care at the clinic, and to ensure all their clinical needs were addressed over time.

### *3.2. Quantitative Results*

Of the 2325 email addresses, 432 bounced back as invalid, and 16 recipients emailed to state they did not treat patients with HF and hence were excluded. There were seventy-three respondents who completed the survey (39 after COVID-19 pandemic onset); their characteristics are shown in Table 9. While 6 (8.0%) respondents did not report their province, responses by province are shown in Figure 5.

There were forty-nine (87.5%) providers who reported they would refer hypothetical patient 1, with reasons including: need more specialized care to manage this patient's HF / complexity (e.g., renal issues; n=33), medication titration is required (n=11), patient symptoms and quality of life (n=7), high-risk patient (n=6), and need for tests (n=4), among other

responses. For hypothetical patient 2, thirty-seven (66.1%) providers reported they would refer the patient, with reasons including: requires medication titration (n=16), self or specialist can manage this patient, and would refer to HF clinic later if needed (n=14), patient needs more specialized care (n=10), consider candidacy for devices or advanced testing needed (n=7), patient needs clinic care given symptom burden, needs home monitoring or other support (n=5), among other responses (with 4 reporting referral to clinic was not needed for this patient).

As shown in Table 10, most attitudinal items were considered applicable (i.e., inapplicability ratings above 30% for items “variation in inclusion / exclusion policies across clinics renders it difficult to refer appropriate patients” and “we offer multi-disciplinary, chronic care in our practice, so referral to an HF clinic is unnecessary” only; range 13.7 to 31.5%, mean  $15.7 \pm 3.2$ ). The greatest positive factors affecting referral practices were: perceiving HF clinic is particularly valuable for complex patients, that all high-risk HF patients should be managed in specialized, multi-disciplinary clinics and acknowledging evidence of benefit of HF clinics to be very strong. The most important valid factors affecting referral practices were: only referring certain types of HF patients, that wait times to get in to the HF clinic were too long and being unwilling to refer if the provider perceived that the patient would not follow through with the referral.

The greatest negative factors affecting referral practices were: being skeptical about clinic benefits, patients reporting a bad experience and believing that they are better equipped to handle patients with HF than HF clinics (Table 10). The greatest negative factors are shown by province in Figure 5. “Other” factors affecting referral of patients to HF clinics respondents listed included: patient-related barriers (e.g., fatigue, age, functional status, transportation, language; n=5), provider awareness and knowledge (n=4), medication titration (n=4), issues with

available clinics (e.g., does not meet patient preference, does not consider comorbidities, no long-term management; n=3), only send specific patients to clinics (e.g., based on complexity, disease severity; n=3), and timeliness (n=2), among other factors.

Responses to the attitudinal items were not normally distributed. Table 10 also displays the association of attitudes with provider profession. Cardiologists were more likely to strongly endorse that the HF clinic referral criteria were very clear, that they always refer patients with HF who meet the clinic referral criteria, that they refer most of their patients with HF to cardiac rehabilitation, and finally that there are processes or supports within their practice setting to automatically trigger an HF clinic referral or for HF clinic referral form completion and submission when it is indicated than other specialists. Cardiologists were less likely to endorse that they were not familiar with HF clinic sites outside their geographic area, and that the variation in inclusion / exclusion policies across clinics rendered it difficult to refer appropriate patients than other specialists. As shown, there were no significant differences in negative attitudes by specialty (but there was a trend regarding availability of multidisciplinary care within their practice).

Responses to COVID-related items are shown in Table 11. Over one-third reported the pandemic impacted their referral practices, most commonly because of limits to in-person care and patient concerns (~10% each). Approximately one-quarter of clinics communicated with referring providers about changes in care access. Most commonly these were related to: transition to phone calls / hybrid care (n=5); limited capacity and increased wait times (n=4), and limits to visits or patient acceptance (n=3), among other reasons. When asked what had changed regarding support for higher-risk HF patients in terms of accessible community care due to COVID-19, responses included: more virtual care (n=8), less access to care (n=7), and limits of

virtual care (n=5), among other changes; 6 responded there were no changes. Finally, providers estimated less than 40% of their patients could accommodate virtual care visits, with the most common challenges being: lack of technological skills, no internet access, or limited language or cognitive abilities (Table 11).

#### 4 DISCUSSION

To our knowledge, this is the first study investigating referring healthcare provider's perceptions and attitudes towards HF clinic referral – key considering a referral is required for patients to access these clinics, and that clinics are under and inequitably utilized despite their benefits.<sup>49,50</sup> While multi-level factors impede appropriate use of clinics,<sup>92</sup> healthcare provider encouragement facilitates patient attendance at clinic visits, underscoring the importance of referring providers for optimal patient access.<sup>102</sup> Major themes identified through qualitative interviews with various referring providers were knowledge about HF clinics and their characteristics, their clinical expertise, communication and relationship with their patients, as well as clinic referral processes and care continuity. Most providers would refer the hypothetical patients, for appropriate and valid reasons (e.g., need for advanced testing for device candidacy). Many cardiologists appropriately recognized that many patients do not need the subspecialty clinic care upon diagnosis, and are capable of and comfortable with optimizing medical therapy. Facilitators (e.g., perceiving value in clinic care for managing high-risk, complex patients) as well as legitimate (e.g., COVID-19, wait times, patient-related logistical barriers such as transportation) but also negative attitudinal (e.g., bad patient experience, skepticism of benefits) barriers to appropriate referral were identified.

Many of the main factors impacting referral identified through the qualitative aspect of the study, the open-ended responses to the case scenarios as well as the adapted

PACRR attitudinal item ratings were consistent with those reported in reviews on physician factors affecting cardiac rehabilitation referral,<sup>57,103</sup> results from PACRR rehabilitation studies,<sup>104</sup> as well as the qualitative research on system, clinic and patient level factors affecting appropriate HF clinic use.<sup>92</sup> For instance, prominent considerations in this literature comprise beliefs about the benefits of the clinics, awareness of clinic sites and referral processes, referral norms and within-institution supports for referral, perceived patient motivation and other patient-related logistical barriers (e.g., distance / transportation). Also consistent with previous cardiac rehabilitation literature were significant differences in referral issues by provider specialty.<sup>94</sup> In both cases, the primary care providers had greater challenges impeding appropriate referral, such as lack of familiarity with clinic locations and their referral processes, as well as clinic-to-clinic service variability. COVID-19 complicated care access, as it did across many health conditions.<sup>105</sup> There are several implications stemming from the findings. Some facilitators to appropriate and optimal use of HF clinics are proffered in our earlier qualitative work.<sup>92</sup> These included better integration across the continuum of care, clinic triage tools for the emergency department,<sup>88</sup> clinic standardization as appropriate, clinic marketing to referrers in the catchment area, sufficient clinic resourcing to support their timely consideration of referrals and patient intake as well as communication with referring providers, in addition to optimizing hybrid, patient-centered care. Many of the facilitators identified directly address the issues raised herein. This includes wider dissemination of guideline recommendations on who should be referred to HF clinics (e.g., I-NEED-HELP<sup>13</sup>), particularly for the non-cardiologists. Indeed, a recent qualitative synthesis on general practitioners' perceptions on improving HF care identified that there is uncertainty about clinical practice guidelines and which one to follow is one of the major challenges.<sup>106</sup>

Clearly the within-institution referral processes and supports were major factors supporting referral, and this is supported in the cardiac rehabilitation field as well; there are reviews<sup>107</sup> and randomized trials<sup>108</sup> showing the benefit of systematic/automatic referral on clinic utilization. This is more easily facilitated in the current era with the almost ubiquitous use of electronic medical records. A Cochrane review also demonstrated the importance of face-to-face provider encouragement of patients to attend the clinics in increasing their utilization.<sup>109</sup> A corresponding implementation tool is available, that may be adapted for HF clinics as well.<sup>110,111</sup> In addition to more health system-level considerations, patient-level barriers must continue to be addressed too.

### ***Limitations***

Caution is warranted in interpreting these results. First, representative generalizability is not established through qualitative research, so whole purpose sampling was used, and saturation was achieved, applicability of qualitative findings to other settings cannot be known. Second, generalizability is limited due to the poor response rate to online surveys, particularly by physicians.<sup>112</sup> This also raises the possibility of selection bias. To optimize the survey response rate, components of Dillman's Tailored Design Method.<sup>113</sup> were applied, including multiple contacts, personalized mailings and a short questionnaire. In a review of physician response to surveys,<sup>114</sup> the demographic characteristics of late respondents (considered a proxy for non-respondents) were similar to the characteristics of respondents to the first mailing. Moreover, physicians as a group are more homogeneous than the general population with regard to knowledge, training, attitudes and behavior, suggesting that non-response bias may not be as crucial in physician surveys as with the general population.<sup>115</sup> Furthermore, generalizability to

other countries is unknown, particularly to jurisdictions with privately-funded healthcare systems, and those in low-resource settings.

Third, prior to and during the interviews, investigators worked to minimize socially-desirable responding and to ensure interviewer neutrality. Fourth, with regard to measurement, hypothetical case scenarios were used to assess referral practices. Previous research similarly using cases examining referral variation has suggested that physicians respond in a manner similar to how they respond to actual cases.<sup>115</sup> These justifications lend credence to the validity and generalizability of our findings to the Canadian context, however replication is warranted. Future research is needed to investigate provider attitudes and perceptions affecting their real-world HF clinic referral practices across a period of time. Also related to measurement, the survey administered was adapted from a psychometrically-validated tool,<sup>93</sup> due to unavailability of an applicable measure. Therefore, reliability and validity of the items cannot be substantiated. Applicability ratings of items supported face and content validity. Fifth, multiple comparisons were performed, which increases the chances of identifying spurious associations as significant; a more conservative p-value was applied to mitigate this. Finally, given the design, causal conclusions cannot be drawn.

In conclusion, this first study investigating perceptions and attitudes of healthcare providers regarding HF clinic referral, mixed-methods design were used. The major themes regarding provider referral identified were knowledge about HF clinics and their characteristics, providers' clinical expertise, their communication and relationship with their patients, as well as clinic referral processes and care continuity. The greatest positive factors affecting referral decisions were perceiving clinics to be valuable for the management of complex, high-risk

patients; the greatest negative factors included skepticism regarding clinic benefit and a bad experience with a clinic. Non-cardiologists may require more supports to facilitate optimal clinic referral. There are several means by which some of the factors identified can be mitigated, but ultimately the system needs to be well-resourced and patients supported to optimally self-manage their condition and care journey.

Figure 4: Main themes from qualitative interviews

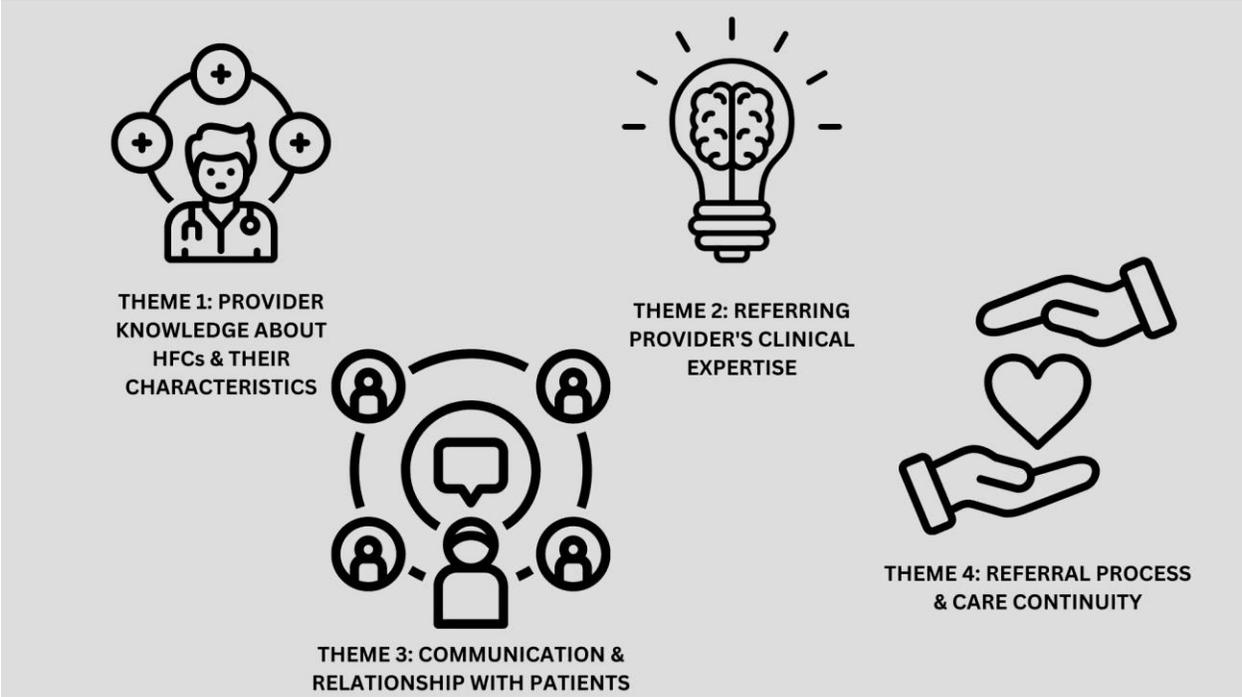
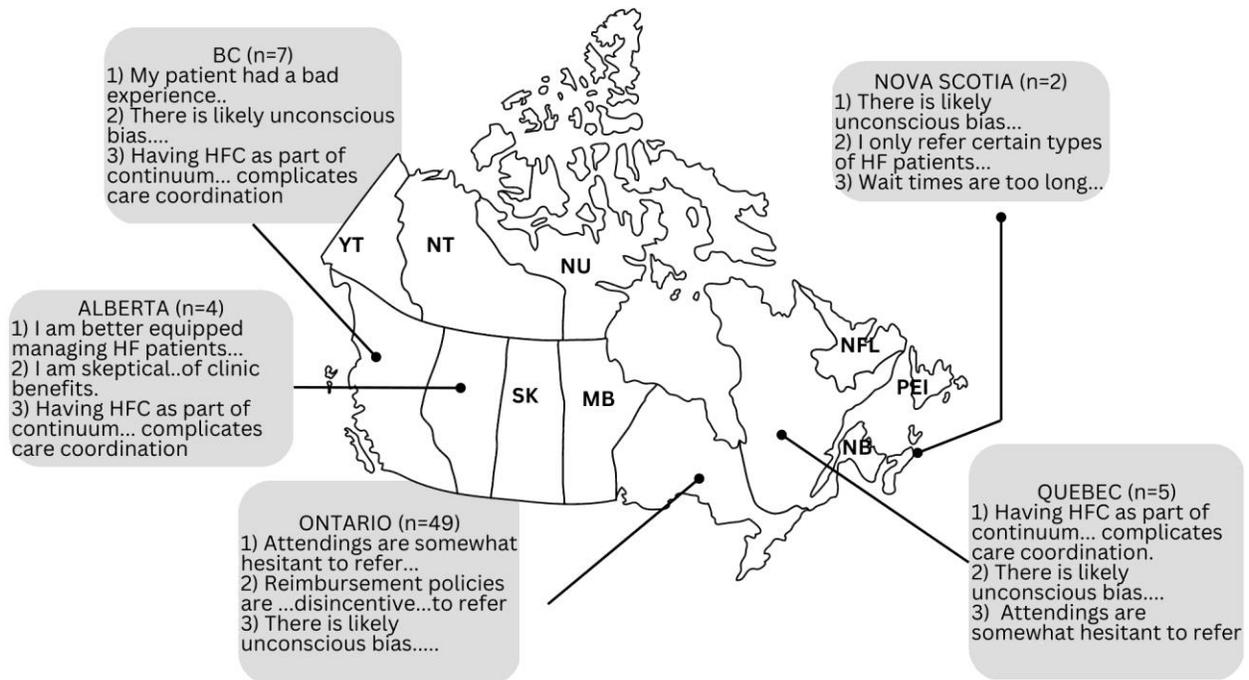


Figure legend: HFCs, heart function clinics.

Figure 5: Survey Response and Greatest Negative Factors Affecting Heart Function Clinic Referral by Canadian Province



MB, Manitoba; NB, New Brunswick; NFL, Newfoundland and Labrador; NT, Northwest Territories; NU, Nunavut, PEI, Prince Edward Island; SK, Saskatchewan; YT, Yukon Territories.

Note: No known survey responses from NB, NT, NU, PEI and YT (PEI and NU have no heart function clinics), although province was not recorded in six surveys. Top negative factors not shown in provinces with only 1 response (i.e., MB, NFL).

Figure 6: Infographic of themes and subthemes of referrers interviews

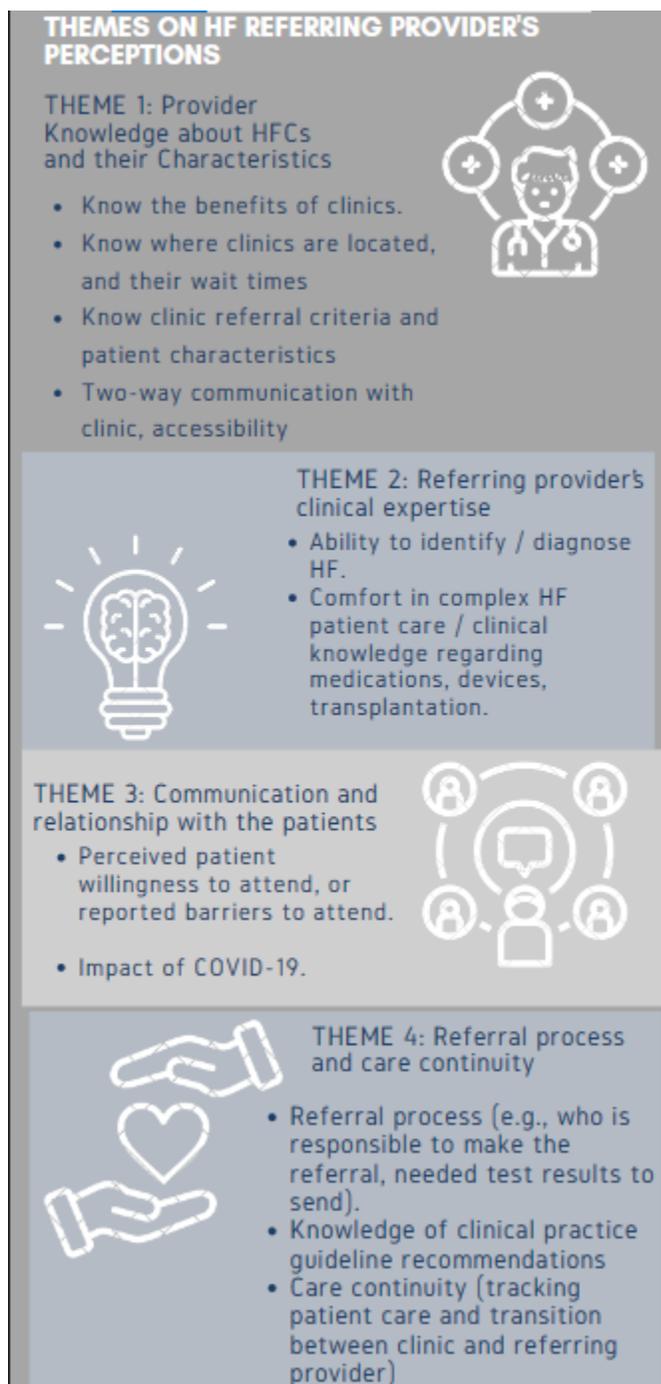


Table 7: Characteristics of referring providers who participated in qualitative interviews

<b>Participant ID</b>	<b>Sex</b>	<b>Institution Type (has HF clinic)</b>	<b>Specialty</b>
1	M	Yes	Cardiologist
2	M	Yes	Cardiologist
3	M	Yes	Internal Medicine
4	M	Yes	Cardiologist
5	M	Yes	Family Physician
6	F	Yes	Cardiologist
7	F	Yes	Cardiologist

HF, heart failure; M, male; F, female.

Table 8: Themes and sub-themes emerging from the referring HF provider interviews, with exemplar quotes.

Themes	Sub-themes	Selected Illustrative Quotes (participant identification number)
<p>Provider knowledge about HF clinics and their characteristics</p>	<p>Know benefits of clinics</p>	<p>“I feel patients really benefit from subspecialized care even when they're relatively routine cases because the subspecialist has the infrastructure around them.” (4)</p> <p>“But you know, the issue is if the HF clinic is gonna say the same things that I'm already doing. It [often] does. It's not a value add to the patient or the system to send to an HF clinic.” (3)</p> <p>“On discharge, right... so we admit a patient with HF. They don't have good follow-up. They don't have a cardiologist or they don't have someone who knows them. So, we refer them to the HF clinic.” (3)</p>
	<p>Know where clinics are located, their wait times</p>	<p>“HF clinics aren't one of those top things that we think about. So, if you were to ask me ‘where are all your HF clinics?’ I don't think a lot of our primary care doctors would know... We don't know where the HF clinics are and we don't know when to refer as opposed to a normal cardiologist.” (5)</p> <p>“I know there's one at [XXX] and [YYY] and [ZZZ] obviously.... One of the issues [is] access and capacity. So you know, often we will be worried about a patient and wanna see them more frequently .. [as] sounds like they're heading towards decompensation; But there's just not space to bring them in.” (2)</p> <p>“Well there's a capacity [issue], so they can only see a certain number of patients on certain days. So if I wanted the patients seen tomorrow, that's probably not gonna happen.” (1)</p> <p>“Now, I'd love to learn, but as far as I know, there's no repository of... HF clinics in the [region]. I don't know of a resource like that. That would be awesome... I don't think that exists.” (3)</p>

	<p>Know clinic referral criteria with regard to patient clinical characteristics, etc.</p>	<p>“Yes, the clinics I mentioned also vary in the type of patients they receive. For example, at [XXX], they only accept patients with an EF less than 30. It is different for [YYY] and other clinics.” (1)</p> <p>“Patients that I encounter either in [XXX] practice or on my inpatient work at [YYY] hospital... if they've been admitted with a diagnosis of HF or if HF is a big part of their clinical syndrome, then I'm pretty liberal, pretty quick to refer them.” (4)</p> <p>“...In other words, it's not clear when we should be referring to HF clinic. When should we? If they're on all the drugs? If they're still having shortness of breath, then I'll [refer] them out.” (5)</p> <p>“...basically the criteria is on the referral [form]. So, it's specifically says you have to have a diagnosis of HF [for six months] and you have to have a recent hospitalization or [be at] high risk.” (7)</p>
	<p>Two-way communication with clinic, accessibility</p>	<p>“I usually fax and then if urgent I will send an email... But the traditional ways of referring patients, a fax, those are the real barriers.... ” (1)</p> <p>“I would say the main barrier is time and like the lack of physical space and people to see the patients quickly.” (1)</p> <p>“And the truth is when I need a HF clinic, I kind of need it yesterday. I don't need it in four weeks from now. And so, my window of who I refer to HF clinic is a little bit narrower than maybe a family doctor or someone who doesn't see HF on a regular basis.” (3)</p> <p>“So, we're a close type of group... It will almost always be a direct personal conversation and an e-mail, and [referral] form as well to make sure that documentation is there ... And almost always if you add that personal approach, they say yes.” (4)</p> <p>“We used to have a nurse navigator, an HF nurse in hospital, which was excellent. She would also provide contact information .. liaise with patient’s primary care practitioner. Unfortunately, she got sick, and the hospital has decided not to replace her, which is quite unfortunate.” (2)</p>

		<p>“One of the very real [barriers] is, when you do know the people working in the HF clinic quite well and know how stretched and overworked they are, then you actually feel reluctant to add to their misery by sending another patient.” (4)</p> <p>“I think ease of access is critical.... Patients have to [access] the [clinic] every two to three weeks if they need to avoid those hospitalizations and avoid those ER visits. Otherwise, what's the point?” (3)</p>
Referring provider’s clinical expertise	Ability to identify / diagnose HF	<p>“We're still having a hard time figuring out if it's HF or not [in the primary care setting]. I know that sounds kind of weird, but patients don't complain a lot, they just do less and less. They get shorter of breath... Is it chronic obstructive pulmonary diseases? Angina? It's not so clear. It's not like I have a whole bunch of HF patients that I am sitting on.. more like HF hidden inside these patients, and I may or may not be able to pick it out. Because ... we're not doing echo[cardiogram]s on all these people.” (5)</p> <p>“A lot of these patients are actually very frail and very comorbid. HF might be one of the things, and you know, they present with shortness of breath. But geez, they've got chronic obstructive pulmonary diseases, you know like it's like is that really HF?” (6)</p> <p>“Even a flight of stairs; like 3 steps. He's short of breath, but he doesn't complain because he just keeps lowering what he's doing. So, I think that's one of the problems: patients don't realize that they're getting worse... so I think that awareness needs to be there.” (5)</p>
	Comfort in complex HF patient care / clinical knowledge regarding medications, devices, transplantation	<p>“So, I only refer HF patients who I feel uncomfortable looking after, and those who I think will have event... who I'm in need of help with and who are sort of younger HF patients [who need] surgical interventions ...” (3)</p> <p>“I see my own HF patients. The only reason for me to refer a patient would be if I think they needed a transplant...I only refer the advanced, late-stage patients and so that's a very tiny proportion I see in total.” (1)</p> <p>“But you know, an HF clinic is a relatively precious resource; HF is a very common condition. If every patient who met guidelines for referral to a HF clinic [was referred], we would have to build a whole bunch more HF</p>

		<p>clinics and --like I said --I am comfortable managing, so..." (3)</p> <p>My practice is that if they're pretty robust, not frail, I'm fairly comfortable with medication titration at my office. And I have a bit more flexibility in terms of how often I can see them in the office. So, if it is just a new diagnosis [with] reduced EF, then I don't think the patient necessarily needs to be [referred to] the HF clinic." (2)</p>
<p>Communication and relationship with the patients</p>	<p>Perceived patient willingness to attend, or reported barriers to attend</p>	<p>"So they have to have emails and it's all online, and a lot of the older people doesn't know technology but the son or the daughter [knows] ... they [help] connect up and have a sort of face-to-face assessment." (5)</p> <p>"And so, there are some patients .. a phenomenon of medical fatigue... They see a lot of doctors, they go for a lot of tests. You know, you can often sense who these people are ... They express an extreme reluctance to add any new medications, or modify the dose of existing medications ... I know it's probably not that much point in getting them in front of a different doctor, [who] is gonna add three more drugs. So I do factor that in." (4)</p> <p>".. some of these patients are in long-term care homes. So it's hard to have them assessed, because again, of the way their care is done in long-term care." (6)</p>
	<p>Impact of COVID-19</p>	<p>"Like, of course, COVID had an impact... like HF is not in general something that can be done virtually. You can do some virtual. ... automated vital signs systems [online], where you can ... track people's vital signs, medications all on a computer. But you gotta listen to people's lungs .... measure the Jugular venous pressure ... It's not always easy to do it virtually. And you know, you can always throw more diuretics at a patient. But, without seeing them, you don't really measure the impact." (3)</p> <p>"I pivoted very much to virtual care ..very early in the pandemic... Patients have some difficulties ... if they're elderly, but .. some adult children would take a 1/2 day off work..." (4)</p> <p>"It's probably more impact on patients who need tuning up periodically but can't get access, because either they have COVID or their doctor's not seeing patients. So, I think it has been a negative impact on people seeking care and getting their care." (3)</p>

		<p>“So, I think COVID-19 was very scary for people with HF ‘cause we thought that they're all gonna die ... ” (5)</p>
Referral process & care continuity	Referral process (e.g., who is responsible to make the referral, needed test results to send)	<p>“It would be nice if there's a single standardized province wide referral form... kind of the way we had for cardiac cath[eterization] for many years.” (4)</p> <p>“So I have my admin support team chase that [referral] down to make sure that it happened” (3)</p>
	Clinical guideline recommendations for HF clinic referral	<p>“I recall we have a like a figure posted in the CCS HF guidelines that suggested ... when you should send the patient ... But to be honest, I'm not really sure, I am not aware of, specific guidelines” (2)</p> <p>“... And so, I think guidelines [need to be] more transparent about what HF clinics want to see ... Would be helpful.” (3)</p> <p>"The problem is for people who don't meet that criteria, but still would benefit from an HF clinic” (4)</p>
	Care continuity (tracking patient care and transition between clinic and referring provider)	<p>“You have to be tight on your own systems, right? For example, if you don't keep track of things, you'll lose... We have a separate file for pending consults, received consults. Do you have a system to track who's waiting for what? I mean, as the doctor, I can't be chasing referrals on.” (3)</p> <p>“Most of the time if patients have been to a HF clinic, anything to do with their heart, they think it's for that place ... because they figure that, that's where their care is going to be.... So, the linkage is not that great in terms of ‘here are the things that you need to do and here's what primary care is gonna do. And here's what the HF clinic is going to do’.” (5)</p> <p>“So, I continue to manage [after] their referral ... What often happens is that you make the referral and the patients clinical situation changes; they get sick. So they bounce back to the ER or they bounce back to my outpatient clinic...” (3)</p> <p>“.. The loop is hard to close, right? So, you stand there for [clinic acceptance]... So, then you have to chase, right? There's no immediate gratification. Like when I order a delivery on Amazon, I know that delivery has been accepted. I get an e-mail right away ... ‘order is in process’;</p>

		<p>Another e-mail when the thing is being shipped ... I can track my shipment. I can't do any of that [here].” (3)</p> <p>“It happens a lot... I think they're rejecting people who are out of catchment” (3)</p>
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CCS, Canadian Cardiovascular Society; COVID, Coronavirus disease 2019; EF, ejection fraction; ER, Emergency room/ department; HF, Heart failure;

Table 9: Sociodemographic, occupational, and institutional characteristics of clinic-referring provider survey respondents

	n (%) or mean $\pm$ SD
<i>Sex</i>	
Female	25 (35.2%)
Male	45 (63.4%)
<i>Profession</i>	
Physician	63 (91.3%)
Nurse-practitioner	6 (8.7%)
<i>Years of practice</i>	22.5 $\pm$ 11.3
<i>Type of institution</i>	
Hospital	58 (82.9%)
Outpatient-only	12 (17.1%)
<i>Primary specialty</i>	
Cardiologist	34 (54.8%)
Internal medicine	17 (27.4%)
Emergency medicine	7 (11.3%)
Family physician	4 (6.5%)
<i>Institution has an HF clinic (% yes)</i>	60 (85.7%)
<i>Province of practice</i>	
Ontario	49 (71.0%)
British Columbia	7 (10.1%)
Alberta	5 (7.2%)

Quebec	5 (7.2%)
Nova Scotia	2 (2.9%)
Newfoundland and Labrador	1 (1.4%)

HF, Heart Function; SD, Standard Deviation;

Table 10: Referring providers' perceptions and attitudes about referral to Heart Function Clinics

Item	mean $\pm$ SD*	† Not applicable (n, %)	Association with specialty (Cardiology vs other)§	p
<u>Positive Attitudes or Perceptions</u>				
I find referral to HF clinics is particularly valuable for my complex patients (e.g., multimorbidity)	4.2 $\pm$ 0.9	16 (21.9%)	736.5	0.19
All high-risk HF patients should be managed in specialized, multi-disciplinary clinics.	4.0 $\pm$ 1.1	13 (17.8%)	904.5	0.86
The evidence of benefit of HF clinics is very strong.	3.9 $\pm$ 1.1	16 (21.9%)	862.5	0.89
Patient preferences are considered when making referral decisions.	3.8 $\pm$ 0.9	15 (20.5%)	783.0	0.19
My colleagues generally refer their appropriate patients to HF clinics	3.7 $\pm$ 0.9	13 (17.8%)	798.5	0.16
I am satisfied with the communication from the HF clinic summarizing the patient care which they provided.	3.6 $\pm$ 1.0	20 (27.8%)	681.0	0.37
HF clinics are very valuable for addressing end-of-life issues with my HF patients.	3.5 $\pm$ 1.2	14 (19.2%)	728.5	0.07
HF guidelines in Canada are clear on referring patients to HF clinics.	3.3 $\pm$ 0.9	13 (17.8%)	830.5	0.39
I am more inclined to refer my patients with systolic dysfunction.	3.2 $\pm$ 1.3	14 (19.2%)	867.5	0.61
The criteria for referral to HF clinics is very clear to me	3.2 $\pm$ 1.2	13 (17.8%)	716.0	<0.01
I always refer my HF patients who meet the clinic referral criteria.	2.9 $\pm$ 1.0	16 (21.9%)	644.5	<0.01
I refer most of my HF patients to cardiac rehabilitation	2.6 $\pm$ 1.2	15 (20.5%)	691.5	<0.02

Primary care providers should be referring to HF clinics.	2.6 ± 1.2	11 (15.1%)	864.0	0.10
I only refer my patients who have been to the emergency department to an HF clinics.	2.3 ± 1.0	17 (23.3%)	826.0	0.99
<i>Mean subscale score</i>	3.5 ± 0.4		858.0	<0.02
<u>Valid Barriers to Referral</u>				
I only refer certain types of my HF patients to clinics	3.7 ± 1.2	14 (19.2%)	855.5	0.80
The wait times for patients to get in to the HF clinic are too long	3.3 ± 1.2	12 (16.4%)	887.5	0.27
I will not refer a patient if I believe the patient will not follow through with the referral	3.2 ± 1.2	15 (20.5%)	754.0	0.10
I do not always refer patients who meet the referral criteria, as sometimes they report barriers to attending, such as lack of transportation	3.2 ± 1.1	17 (23.3%)	683.5	0.13
I do not always refer patients who meet the referral criteria, because there are not enough HF clinics	3.1 ± 1.3	20 (27.4%)	671.0	0.94
I am not familiar with HF clinic sites outside my geographic area, so cannot readily refer my appropriate patients who come from afar.	3.1 ± 1.3	18 (24.7%)	626.0	<0.02
There is so much variation in HF clinics, it is difficult to be certain what each one has to offer or delivers.	3.1 ± 1.2	20 (27.4%)	725.5	0.94
Variation in inclusion / exclusion policies across clinics renders it difficult to refer appropriate patients.	3.0 ± 1.2	23 (31.5%)	587.0	0.04
Patients seem to have so many barriers to going to HF clinics	3.0 ± 1.1	10 (13.7%)	977.5	0.50

There are processes within our practice setting to support HF clinic referral completion and submission	2.7 ± 1.4	13 (17.8%)	765.5	<0.02
I only refer my high-risk patients to HF clinics	2.6 ± 1.3	14 (19.2%)	898.0	0.97
Some of my patients would benefit from HF clinics, but there are no clinics within their geographical area, so I cannot refer them.	2.4 ± 1.2	21 (28.8%)	620.0	0.18
There are processes within our practice setting to automatically trigger an HF clinic referral when it is indicated	2.2 ± 1.2	15 (20.5%)	578.0	<0.001
<i>Mean subscale score</i>	2.9 ± 0.3		940.5	0.25
<u>Negative Attitudes or Perceptions</u>				
I am skeptical about the benefits of HF clinics.	4.1 ± 0.9	14 (19.2%)	810.5	0.13
My patients have had a bad experience with a HF clinic	3.9 ± 1.0	17 (23.3%)	759.0	0.49
I believe I am better equipped to handle my HF patients than HF clinics	3.9 ± 0.9	17 (23.3%)	680.0	0.28
We offer multi-disciplinary, chronic care in our practice, so referral to an HF clinic is unnecessary	3.8 ± 1.1	23 (31.5%)	577.5	0.07
Reimbursement policies are a financial disincentive to HF clinic referral	3.8 ± 1.0	20 (27.4%)	653.0	0.15
Having HF clinics as part of the continuum of care for HF patients can often complicate care coordination.	3.6 ± 1.1	12 (16.4%)	912.0	0.78
Attendings are somewhat hesitant to refer patients to HF clinics	3.5 ± 0.9	15 (20.5%)	798.0	0.34

There is likely some unconscious bias in referral of patients to HF clinics at our organization (e.g., sex, socioeconomic status)	3.3 ± 1.2	14 (19.2%)	819.0	0.42
<i>Mean subscale score</i>	3.7 ± 0.7		980.0	0.86

\*items are scored from 1 “strongly disagree” to 5 “strongly agree” and higher values indicate more positive sentiments.

‖with the reverse-scoring of these items, higher values indicate more positive sentiments.

HF, heart failure; SD, standard deviation.

§Wilcoxon rank-sum test values.

‡ Participants responded ‘not applicable’ option for each attitudinal item

Table 11: Perceived impact of COVID-19 pandemic on heart function clinic referral process

	n (valid %)
1. Has COVID-19 impacted your referral of patients to HF clinics? (% yes)	13 (33.3%)
1a. I am more likely to refer as I know some of the clinics have technology to better monitor patients remotely, thus reducing physical contact within the healthcare system.	2 (3.8%)
1b. I am less likely to refer as I am unsure how they would safely take on new patients given attempts to limit in-person patient care.	5 (9.4%)
1c. I am consulting with patients more regarding whether they feel safe being referred.	5 (9.4%)
1d. Other	2 (3.8%)
2. Have HF clinics where you refer patients been in communication with you regarding any changes in care access or referrals given COVID-19?	10 (25.6%)
3. Do you perceive your patients would be able to have virtual specialty HF outpatient care visits?	
3a. Yes, mostly	20 (37.7%)
3b. Quite a few patients have no internet access, but could do phone visits	17 (32.1%)
3c. Quite a few patients have unreliable or slow internet access	9 (17.0%)
3d. Quite a few patients do not have sufficient technological skills to do a virtual care visit, without assistance	21 (39.6%)
3e. Quite a few patients do not have sufficient language or cognitive abilities to do a virtual care visit	12 (22.6%)
3f. Other	2 (3.8%)

||respondents directed to check all that apply.

HF, heart failure; COVID-19, Coronavirus disease 2019.

Note: affirmative responses shown.

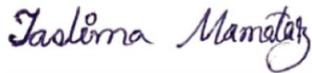
## **CHAPTER FOUR**

PAPER THREE: Heart failure clinic inclusion and exclusion criteria: Cross-sectional study of clinic's and referring provider's perspectives.

CERTIFICATE OF AUTHENTICATION

**Mamataz T, Virani S, McDonald M, Edgell H, Grace SL.** Heart failure clinic inclusion and exclusion criteria: Cross-sectional study of clinic's and referring provider's perspectives (2024). BMJ Open. 14(3): e076664. doi: 10.1136/bmjopen-2023-076664.

The candidate supported in securing ethics approval, data acquisition, formal data analysis and tracking survey responses by provider groups. She made substantial contributions in preparing the first draft of the manuscript, including the interpretation of the results. She incorporated co-authors input in subsequent manuscript versions and responded to journal peer reviewer revisions.



Signature: \_\_\_\_\_

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Sherry L. Grace

## ABSTRACT

**Objectives:** There are substantial variations in entry criteria for heart failure (HF) clinics, leading to variation in whom providers refer for these life-saving services. This study investigated actual versus ideal HF clinic inclusion/exclusion criteria, and how that related to referring providers' perspectives of ideal criteria.

**Design, Setting, Participants:** Two cross-sectional surveys were administered via REDCap-- to clinic providers and referrers (e.g., cardiologists, family physicians, nurse-practitioners) across Canada.

**Measures:** Twenty-seven criteria selected based on the literature and HF Guidelines were tested. Respondents were asked to list any additional criteria. Degree of agreement was assessed (e.g., Kappa).

**Results:** Responses were received from providers at 48 clinics (37.5% response rate). The most common actual inclusion criteria were newly-diagnosed HF with reduced or preserved ejection fraction, New York Heart Association class IIIB/IV, and recent hospitalization (each endorsed by >74% of respondents). Exclusion criteria included: congenital etiology, intravenous inotropes, lack of specialist, some non-cardiac comorbidities and logistical factors (e.g., rurality, technology access). There was greatest discordance for actual versus ideal criteria for the following: inpatient at same institution ( $\kappa=.14$ ), congenital heart disease, pulmonary hypertension or genetic cardiomyopathies (all  $\kappa=.36$ ). One-third (n=16) of clinics had changed criteria, often for non-clinical reasons.

Seventy-three referring providers completed the survey. Criteria endorsed more by referrers than clinics included low blood pressure with high heart rate, recurrent defibrillator shocks, and intravenous inotropes –criteria also consistent with Guidelines.

**Conclusions:** There is considerable agreement on the main clinic entry criteria, but given some discordance, two levels of clinics may be warranted. Publicizing evidence-based criteria and applying them systematically at referral sources could support improved HF patient care journeys and outcomes.

## 1 INTRODUCTION

It is estimated that there are 64 million people living with heart failure (HF) globally.<sup>64</sup> It is a growing epidemic, associated with high mortality, morbidity, and health care costs.<sup>2</sup> Optimal medical therapy, device therapy (where indicated), and patient self-management across multiple health behaviours can improve HF outcomes and quality of life.<sup>12,14</sup>

Given the complexity of HF management, patient-centred, comprehensive and multidisciplinary care is needed.<sup>116</sup> Although there is wide variation in composition and services provided, HF clinics are outpatient sub-specialty centres staffed by a multidisciplinary team, typically offering timely care access to stabilize, optimize and prevent acute decompensation.<sup>8,24</sup> There is compelling evidence supporting reduced all-cause mortality and HF hospitalizations in patients receiving care in HF clinics, with even greater benefits seen in patients having a recent emergency department visit or hospital admission.<sup>72</sup> HF clinics are also shown to be cost-effective.<sup>11</sup> Despite these established benefits, their utilization is low and disparate.<sup>13,16,49,53</sup>

It has previously been suggested that challenges in appropriate use of HF clinics relate to: limited clinic capacity, discordance between clinic referral or entry criteria (i.e., inclusion, exclusion or reasons for rejection) and patient profile, variation in clinic services (and correspondingly limited referring clinician's knowledge of the type of care a clinic provides), selection bias towards younger patients who may benefit from advanced therapies, or perceived patient-level barriers, among other factors.<sup>42</sup> Indeed, one of the main access barriers identified in a recent audit of HF clinics<sup>7</sup> as well as a survey of referring clinicians<sup>117</sup> in Canada was entry eligibility criteria, and hence lack of clarity on which patients are appropriate to refer.

There is some guidance on HF clinic referral criteria in Canada and other jurisdictions,<sup>6,12,16</sup> as well as some explicit guidance from the American College of

Cardiology/American Heart Association/Heart Failure Society of America (i.e., I-NEED-HELP).<sup>13,86</sup> This guidance is not fully consistent however with regard to criteria. The audit showed for example that only 56% of clinics had explicit criteria-- which resulted in many referrals being declined-- but 40% would accept all-comers.<sup>7</sup> Moreover, only 51% of clinics reported accepting recently-discharged patients, diminishing the value of clinics in mitigating exacerbations during that critical period.<sup>87</sup> This audit<sup>7</sup> therefore concluded with a call for more explicit guidance on risk-based HF clinic inclusion and exclusion criteria. Thus, with consideration of clinical practice guideline recommendations,<sup>16</sup> the objectives of this study were to characterize: perceptions of providers at clinics regarding actual versus ideal HF clinic inclusion and exclusion criteria, and how that relates to referring clinician perspectives of ideal criteria.

## 2 METHODS

### *2.1. Design and Procedure*

Two separate cross-sectional surveys were administered online through REDCap.<sup>118,119</sup> the first to providers at HF clinics (appendix D) and the second to clinic-referring providers (Appendix C 2<sup>nd</sup> part) across Canada. To optimize response rate, non-responders were re-sent the surveys a maximum of 3 times. Expert Panel members also supported data collection by personally contacting indicated colleagues to optimize generalizability. The surveys were administered from March - April 2020, then from May to December 2022; recruitment was paused in the interim due to the coronavirus disease (COVID-19) pandemic.

### *2.2. Participants*

For the HF clinic survey, clinics were self-defined. Previous literature suggested there were approximately 128 HF clinics across Canada: 47 in Quebec, 36 in Ontario, 22 in British

Columbia, 11 in Alberta, three in Saskatchewan and four in each of New Brunswick and Nova Scotia, one in Manitoba serving part of Northern Ontario and Nunavut.<sup>16</sup> It is believed there are no clinics in Newfoundland and Labrador, Prince Edward Island, the Yukon or the Northwest Territories. One administrator or provider from each HF clinic was invited to complete the survey. Email contacts for programs in Ontario were available from a previous environmental scan.<sup>15</sup> Programs in other provinces were contacted through our Expert Panel members (e.g., put in touch with coordinator for all clinics in Alberta, British Columbia HF Physician Lead) and searching on the internet. For some jurisdictions, new HF clinics were identified for surveying, but others had potentially closed as emails were no longer valid.

For the clinic-referrer's survey, healthcare providers (i.e., family and emergency room physicians, internists, cardiologists and nurse-practitioners) working in any setting (e.g., inpatient, outpatient) across Canada treating HF patients and eligible to refer to HF clinics were included. Providers who indicated that they did not treat HF patients were excluded. Provider email addresses were purchased from a private company, by specialty (TargetNXT). Overall, 2325 email addresses were acquired: 750 cardiologists (academic and non; all available emails), 200 family physicians, 200 emergency medicine physicians, 200 internists (subspecialty unknown) and 435 nurse-practitioners (although specialty was not known; all available emails). In addition, faculty directories of relevant departments at medical schools in Canada were searched for email addresses to optimize generalizability. Information about representativeness of the sample is reported elsewhere.<sup>117</sup>

### *2.3. Measures*

The first part of the HF clinic survey assessed clinic characteristics (e.g., location, staff, components offered, institution) (Appendix D). Then, 27 clinic referral criteria were assessed.

The criteria were chosen following a review of clinical practice guideline recommendations (see online Table 2 at <https://sgrace.info.yorku.ca/publications/>)<sup>16</sup> and with input from members of the Expert Panel. For each item, respondents were asked whether the item was a clinic inclusion (yes/no) or exclusion (yes/no) criterion. They were also asked for each criterion whether they should ideally be considered an inclusion or exclusion criteria, or whether it should not be considered.

Respondents were also asked if there were any other criteria relevant for their clinic that they perceive should be considered. They were also asked whether their clinic referral criteria were explicitly stated or posted, and whether they had ever changed their criteria due to volume issues. Where they responded yes for each, they were to specify in open-ended fashion.

The referring providers' survey was prefaced with investigator-generated items querying respondent's sociodemographic and occupational characteristics (Appendix C). Thereafter, the same criteria were listed except one (i.e., referred patient was an inpatient at the institution where your clinic resides). Response options ranged from 1 'This should definitely not be considered' to 5 'This should definitely be considered'.

#### *2.4. Statistical Analysis*

IBM SPSS version 28 was used for analysis. All initiated surveys that had any data were included. Descriptive statistics were applied for all closed-ended items in the surveys (i.e., frequencies with percentages; means, and standard deviations). For the former, percentages were computed with the denominator being the number of responses for a specific item. Open-ended responses were content analyzed.<sup>101</sup> Kappa statistics were computed to calculate concordance between each actual clinic inclusion/exclusion criteria versus their perceived ideal criteria.

### *3.1. Respondent Characteristics*

Responses were received from 48 HF clinics (response rate 37.5%; Figure 7). Clinic characteristics are shown in Table 12.

Of the 2325 provider email addresses, 432 bounced back as invalid, and 16 recipients emailed to state they did not treat HF patients and hence were excluded. Seventy-three respondents completed the survey; their characteristics are shown in Table 13.

### *3.2. HF Clinic Referral Criteria*

Nine (25.0%) clinics reported their referral criteria are fully and explicitly stated on their referral form, website and / or clinic marketing materials; 16 (44.4%) clinics reported some criteria are listed and 11 (30.6%) clinics responded criteria are not declared for referring clinicians.

Actual HF clinic criteria are shown in Table 14. As shown, the most common inclusion criteria were: HF with reduced ejection fraction (HFrEF), New York Heart association (NYHA) class IIIB/IV symptoms, recent hospitalization due to HF, newly diagnosed HF and HF with preserved ejection fraction (HFpEF; each endorsed by >74% of respondents); the least common were: recurrent defibrillator shocks, intravenous (IV) inotropes, low blood pressure and high heart rate, patient visiting providers with complaints of persistent shortness of breath at rest and persistently-elevated natriuretic peptides (NTproBNP) (all endorsed by <46% of respondents). The most common exclusion criteria were: patient's HF is secondary to congenital heart disease or pulmonary hypertension (16.1%), required IV inotropes (9.1%) and evaluation for cardiac transplantation consideration (9.7%).

Four (13.3%) clinics reported other inclusion / exclusion criteria applied. For inclusion these were: NYHA class II but patient needs drug or device optimization, and patient has a

specialist to whom the clinic can discharge them. For exclusion they included: long-term care placement; dialysis patients; dementia diagnosis; rural patients, particularly those without reliable phone / internet access; and patient has no fixed address.

Clinics most-commonly perceived the following factors should be clinic referral inclusion criteria: new diagnosis of HF, sub-optimal drug therapy, recent hospitalization due to HF, NYHA Class IIIB/IV and patient at risk of hospital admission (Table 14; all  $\geq 70\%$ ). Sixteen (32.7%) clinics reported they had changed their referral criteria at some point. They described restricting their entry criteria due to volume issues or to facilitate regional standardization, accepting HFpEF patients, elevated NTproBNP, adding requirement that patient must be seen by cardiologist before acceptance, no direct referral acceptance from internist or family physicians, focusing on patients at risk of re-hospitalization upon request from institution, re-referring patients with specific issues to more appropriate clinics (e.g., hypertrophic cardiomyopathy, amyloidosis). Respondents also mentioned communicating wait times to referring providers (and allowing them to flag urgent cases), discharging stable patients back to their referring provider to manage volumes, or discharging patients sooner.

As also shown in Table 14, there was no to slight agreement between actual and ideal ratings for the following clinic referral criteria: referred patient was an inpatient at the institution where the clinic resides (i.e., this is common practice, but clinics did not perceive it should be). There was only fair agreement between actual and ideal ratings for the following clinic referral criteria: patient's HF secondary to congenital heart disease or pulmonary hypertension and patient with genetic cardiomyopathies (more often perceived the latter should not be a criteria). There was moderate agreement between actual and ideal ratings for the following clinic referral criteria: HFpEF, patient needs self-management support; persistently-elevated natriuretic

peptides, comorbidities, HF<sub>r</sub>EF, amyloidosis, edema despite escalating diuretics, IV inotropes, and medication consult needed (i.e., titration, changes, drug interactions); for all but the latter they were more often actual criteria than perceived ideal. There was substantial agreement between actual and ideal ratings for the following clinic referral criteria:  $\geq 2$  HF-related hospitalizations, patient at risk of hospital admission, one emergency department visit due to HF in the last three months, cardiac transplantation consideration, recurrent defibrillator shocks, progressive intolerance or down-titration of medications needed, end-organ dysfunction/ worsening renal or liver function related to HF, low blood pressure and high heart rate, stage D HF, and patient complaints of persistent shortness of breath at rest. Finally, there was almost perfect agreement between actual and ideal ratings for the following clinic referral criteria: recent hospitalization due to HF, new diagnosis HF, NYHA Class III<sub>B</sub>/IV symptoms, and HF patient requires rhythm device. For the most-highly endorsed ideal clinic criteria, agreement with actual criteria was almost perfect or substantial, except in the case of sub-optimal drug therapy where it was moderate. This suggests clinics perceive they should more often be supporting implementation of guideline-directed medical therapy than they are.

Clinic-referring provider ratings of each referral criteria are also shown in Table 14. Providers most-commonly perceived the following criteria should be applied: cardiac transplantation consideration,  $\geq 2$  HF-related hospitalizations, stage D HF, NYHA Class III<sub>B</sub>/IV symptoms, IV inotropes, and end-organ dysfunction/ worsening renal or liver function related to HF. While all criteria were rated quite highly, the least-strongly endorsed were: new diagnosis of HF, patient complaints of persistent shortness of breath at rest, persistently-elevated natriuretic peptides, progressive intolerance of medications and HF<sub>p</sub>EF.

Finally, as shown in Table 14, referring providers gave high importance ratings to many common actual HF clinic referral criteria (e.g., HFrEF, NYHA Class IIIB/IV symptoms, and recent hospitalization due to HF). Yet, there were some cases where referrers gave high importance ratings to criteria which were not as commonly applied in clinic practice (e.g., low blood pressure and high heart rate, recurrent defibrillator shocks, and IV inotropes). There was also some agreement between clinics and referring providers on what criteria *should* be applied. Referring providers gave high importance ratings to many referral criteria which clinics also often perceived should be applied (e.g., recent hospitalization due to HF, NYHA Class IIIB/IV symptoms, and medication consult needed). However, they also gave high importance ratings to criteria which were not as commonly perceived as important to clinics: IV inotropes, HF patient requires rhythm device, genetic cardiomyopathies, low blood pressure and high heart rate as well as comorbidities.

#### 4 DISCUSSION

HF clinics are proven to reduce mortality and morbidity, where they are accessed. There is lack of clarity and some incongruence in Clinical Practice Guideline direction on which patients should receive care in HF clinics, variation in HF clinic entry criteria, resulting in understandable confusion on the part of referring providers. This study aimed to examine perceptions of optimal entry criteria –inclusion and exclusion-- for HF clinics. Most common HF clinic inclusion criteria were newly-diagnosed HFrEF, NYHA class IIIB/IV, recent HF-related hospitalization and need for medication optimization or consultation; these are consistent with guideline recommendations.<sup>13,86</sup> There was congruence in clinic and referring provider perceptions of these HF clinic entry criteria, but referrers also gave greater importance to the additional guideline-

recommended criteria<sup>13</sup> of low blood pressure along with high heart rate, recurrent defibrillator shocks, and IV inotropes than HF clinics.

To our knowledge this is the first quantitative study on actual and ideal HF clinic entry criteria as well as exclusion considerations, although there has been a review on guideline recommendations for entry criteria<sup>16</sup> (with more recent guidance by the Heart Failure Society of America (HSFA)<sup>90</sup>, primary studies on the clinical characteristics of patients who access them<sup>53</sup>, and some related qualitative research.<sup>92</sup> In line with recent recommendations from the HFSA,<sup>120</sup> among others,<sup>90</sup> it appeared respondents perceived there are two types of HF clinics needed: standard and advanced or specialized (e.g., device candidacy assessment; home inotropic therapy, heart transplant) care. If such a model were applied, likely the findings herein could be used to inform differential referral criteria for these clinic types. Indeed, HSFA's practical guide suggests all HF clinics be resourced to manage Stage B and C patients<sup>13</sup> with HFrEF or HFpEF, as well as related cardiac comorbidities. The more advanced clinics could manage Stage D patients, including patients undergoing or with mechanical circulatory support and/or transplantation.

With regard to inclusion criteria, there seems to be agreement amongst clinic and referring providers (as well as with evidence-based guideline recommendations),<sup>86,90</sup> on the criteria shown in Figure 2. Indeed, these are part of the I-NEED-HELP referral decision-making acronym from American Guidelines<sup>8,13,86</sup> or the more recent HSFA Practical Guide (see Table 4).<sup>90</sup> Given natriuretic peptide measurement is now more widely available,<sup>7</sup> it is likely this should be an entry criteria as well; this likely did not figure prominently in the results given some data were collected some time ago before the COVID-19 pandemic.

HF clinic exclusion criteria were also appraised herein, but clinician judgment of individual cases must continue to be applied. These included non-cardiac or non-clinical concerns such as having a healthcare provider to whom the patient could eventually be discharged from the HF clinic, consideration of non-cardiac comorbidities as well as some social determinants of health. In the current era, patient's technology ability and access were also important considerations. Interestingly, some clinics reported a guideline-recommended entry criteria as an exclusion criterion, including for example IV inotropes. Overall, research is needed to explore whether these are the best HF clinic entry criteria based on evidence of patient benefit through primary studies and meta-regression analyses for example, but also considering cost-effectiveness and feasibility or implementability.

The implications stemming from this work are numerous. First, as promoted in the 2021 Practical Guide of the HSFA,<sup>90</sup> HF clinics need to more explicitly and transparently publicize their entry criteria with all potential referring providers in their catchment area. Given many HF clinics perceived their entry criteria should be changed, active and ideal clinic-specific inclusion and exclusion criteria specifically should be explicitly publicized. The HSFA Practical Guidance also suggests HF clinics set up “automated electronic medical record-based referral alerts” using the agreed criteria.<sup>90</sup> Consistent application of the entry criteria could help overcome some of the inequities observed in HF clinic access.<sup>53</sup>

Second, it seemed that some clinicians were highly capable of managing HF patients without an HF clinic even as their complexity increased, while others were not comfortable so were needing to refer most HF patients. The degree to which further training needs play a role

here versus supporting standard and advanced clinics to address both scenarios warrants further consideration.

Third, better system-wide coordination is needed, given one-third of HF clinics reported having to change their entry criteria-- sometimes on the basis of new research (e.g., accepting HFpEF), but commonly due to inability to handle the volume of referrals received in a timely manner. Ontario's "spoke-hub-node" model is a demonstrated example of how this might be achieved.<sup>85</sup> Within the system, a dashboard showing all HF clinic types with their entry criteria along with average wait times could be useful. Moreover, this could facilitate more efficient triage of cardiac patients to the most applicable clinics, including other subspecialty clinics (e.g., cardiomyopathies, amyloidosis or even cardiac rehabilitation).<sup>49</sup>

### *Limitations*

Caution is necessary in interpreting these results. Chiefly, generalizability to other countries is unknown due to differences in healthcare system organization, particularly as they relate to HF patient care, as well as clinic organization and reimbursement. Further research in other jurisdictions is needed, particularly those with private healthcare funding where there may be a profit motive to see patients yet not all patients have coverage. There was also wide variation in response rate by province and only one response in three provinces (e.g., Saskatchewan), so generalizability in these provinces may be limited.

Moreover, there was a poor response to the referring physician survey online,<sup>112</sup> which also raises the possibility of selection bias. To optimize the survey response rate, elements of Dillman's Tailored Design Method<sup>113</sup> were applied, including multiple contacts, personalized mailings and a short questionnaire. Physicians as a group are more homogeneous than the

general population with regard to knowledge, training, attitudes and behavior, such that non-response bias may not be as crucial in physician surveys as with the general population.<sup>114,115</sup>

### *Conclusion*

HF clinic referral criteria were investigated, with inclusion criteria primarily being HFrEF, having NYHA class IIIB/IV symptoms, HF-related hospitalization, need for medication consultation and risk of decompensation. While there was wide concordance in actual and perceived “ideal” HF clinic entry criteria based on evidence, need or guideline recommendations, some clinics reported not being able to apply their “ideal” entry criteria, or having to change criteria for reasons other than evidence of patient benefit. Differentially, yet also consistent with HF Guideline recommendations, referring providers perceived stage D HF, IV inotropes, and end-organ dysfunction should trigger HF clinic referral. Exclusion criteria were also forwarded. While more research is needed, publicizing evidence-based criteria and applying them systematically at referral sources could support improved HF patient care journeys and outcomes.

Figure 7: Map showing clinic survey response rate by Canadian Province / Territory



Figure legend:

AB, Alberta; BC, British Columbia; MB, Manitoba; NB, New Brunswick; NL, Newfoundland and Labrador; NS, Nova Scotia; NT, Northwest Territories; NU, Nunavut, ON, Ontario; PE, Prince Edward Island; QC, Quebec; SK, Saskatchewan; YT, Yukon Territories.  
 Note: No known heart function clinics in NL, NT, PE and YT.

Figure 8: Most highly and commonly-agreed heart function clinic entry criteria

- HFrEF
- NYHA Class IIIB/IV
- Sub-optimal drug therapy / medication consult needed
- $\geq 1$  hospitalization due to HF
- Emergency department visit(s) due to HF
- Patient at risk of hospital admission



HFrEF, heart failure with reduced ejection fraction; NYHA, New York Heart Association; HF, heart failure

Table 12: Characteristics of HF Clinic Survey Respondents

	n (%) / mean $\pm$ SD
<i>Province</i>	
Ontario	14 (29.2%)
Alberta	14 (29.2%)
British Columbia	9 (18.8%)
Quebec	5 (10.4%)
Nova Scotia	3 (6.3%)
Manitoba	1 (2.1%)
New Brunswick	1 (2.1%)
Saskatchewan	1 (2.1%)
<i>Institution Staff</i>	
Multiple providers	42 (89.4%)
Single HF expert provider	5 (10.6%)
<i>Components offered*</i>	
Medication titration	45 (93.8%)
Patient education	42 (87.5%)
Supervised exercise	13 (27.1%)
Other	4 (8.3%)
<i>Average duration patient in clinic (months)</i>	24.6 $\pm$ 16.1
<i>Average number of in-person visits / patient</i>	11.4 $\pm$ 6.0
<i>Type of Institution</i>	
Tertiary/quaternary hospital	13 (59.1%)
Community hospital	7 (31.8%)
Primary care	1 (4.5%)
Other	2 (9.1%)
<i>Clinic also treats non-HF patients</i>	3 (13.6%)

\*check all that apply

HF, Heart Failure; SD, Standard Deviation.

Table 13: Sociodemographic, Occupational and Institutional Characteristics of Clinic-Referring Provider Survey Respondents

	n (%) or mean $\pm$ SD
<i>Sex</i>	
Female	25 (35.2%)
Male	45 (63.4%)
<i>Profession</i>	
Physician	63 (91.3%)
Nurse-practitioner	6 (8.7%)
<i>Years of practice</i>	22.5 $\pm$ 11.3
<i>Type of institution</i>	
Hospital	58 (82.9%)
Outpatient-only	12 (17.1%)
<i>Primary specialty</i>	
Cardiologist	34 (54.8%)
Internal medicine	17 (27.4%)
Emergency medicine	7 (11.3%)
Family physician	4 (6.5%)
<i>Institution has an HF clinic</i>	60 (85.7%)
<i>Province of practice</i>	
Ontario	49 (71.0%)
British Columbia	7 (10.1%)

Alberta	5 (7.2%)
Quebec	5 (7.2%)
Nova Scotia	2 (2.9%)
Newfoundland and Labrador	1 (1.4%)

HF, Heart Function; SD, Standard Deviation

Table 14: HF Clinic and Clinic-Referring Provider Ratings of Clinic Referral Criteria

Criteria‡	Is Clinic Inclusion Criterion	HF Clinics Perceive Should be Inclusion or Exclusion Criteria	Clinic agreement for actual vs ideal (interpretation; rank§)	Clinic-referring provider perception of criteria importance*  n=73
1. Diagnosis of heart failure with preserved ejection fraction (HFpEF)	26 (74.3%)	21 (61.8%)	0.60 (moderate; 12)	3.86 ± 1.12
2. Diagnosis of heart failure with reduced ejection fraction (HFrEF)‡	29 (85.3%)	22 (64.7%)	0.48 (moderate; 16)	4.02 ± 0.98
3. 1 Emergency department visit due to HF in the last 3 months‡	22 (66.7%)	19 (59.4%)	0.73 (substantial; 6)	4.27 ± 1.10
4. 2 or more emergency department visits for HF‡	22 (66.7%)	21 (63.6%)	0.66 (substantial; 10)	4.36 ± 1.14
5. Recent hospitalization due to HF‡	25 (78.1%)	23 (74.2%)	0.91 (almost perfect; 1)	4.20 ± 1.10
6. 2 or more hospitalizations due to HF‡	22 (66.7%)	22 (66.7%)	0.79 (substantial; 4)	4.45 ± 1.11
7. Medications need titration, changes are required for optimization, or there may be interactions with other medications	23 (67.6%)	23 (76.7%)	0.43 (moderate; 18)	4.00 ± 1.09

patients are taking, and need some consulting advice (i.e., sub-optimal drug therapy) ‡				
8. Progressive intolerance or down-titration of medications needed‡	17 (51.5%)	19 (59.4%)	0.69 (substantial; 8)	3.86 ± 1.12
9. Patient visiting general cardiologist, internist, or primary care provider with complaints of persistent shortness of breath, even at rest.‡	15 (45.5%)	14 (43.8%)	0.62 (substantial; 11)	3.61 ± 1.00
10. Stage D HF (i.e., advanced, end-stage HF) ‡	19 (57.6%)	18 (54.5%)	0.62 (substantial; 11)	4.39 ± 1.09
11. IV inotropes‡	11 (33.3%)	13 (40.6%)	0.47 (moderate; 17)	4.36 ± 1.14
12. NYHA Class IIIB/IV symptoms‡	26 (78.8%)	23 (71.9%)	0.83 (almost perfect; 2)	4.37 ± 1.07
13. Persistently-elevated natriuretic peptides‡	15 (45.5%)	16 (50.0%)	0.50 (moderate; 14)	3.82 ± 1.08
14. HF is secondary to congenital heart disease or pulmonary hypertension	16 (50.0%)	17 (54.8%)	0.36 (fair; 19)	4.17 ± 1.13
15. New diagnosis HF‡	24 (75.0%)	24 (77.4%)	0.91 (almost perfect; 1)	3.54 ± 1.16
16. HF patient requires rhythm device (ICD, CRT)	16 (50.0%)	15 (46.9%)	0.81 (almost perfect; 3)	4.11 ± 1.19
17. Recurrent defibrillator shocks‡	8 (25.0%)	10 (32.3%)	0.69 (substantial; 8)	4.09 ± 1.37
18. Cardiac transplantation consideration	17 (54.8%)	19 (61.3%)	0.72 (substantial; 7)	4.64 ± 1.05
19. Patient is at risk of hospital admission‡	22 (68.8%)	21 (70.0%)	0.77 (substantial; 5)	3.98 ± 1.14
20. Patient has barriers to behaviour change; needs education and coaching to support self-management‡	20 (62.5%)	14 (45.2%)	0.56 (moderate; 13)	4.04 ± 0.99
21. Comorbidities causing complexity in treatment approach	17 (53.1%)	10 (32.3%)	0.49 (moderate; 15)	4.07 ± 1.03
22. Amyloidosis	22 (68.8%)	14 (46.7%)	0.48 (moderate; 16)	4.21 ± 1.06
23. Genetic cardiomyopathies	17 (53.1%)	12 (38.7%)	0.36 (fair; 19)	4.29 ± 1.06

24. End-organ dysfunction/ worsening renal or liver function related to HF‡	16 (50.0%)	18 (58.1%)	0.68 (substantial; 9)	4.31 ± 1.03
25. Edema despite escalating diuretics‡	22 (68.8%)	17 (54.8%)	0.47 (moderate; 17)	4.16 ± 1.09
26. Low blood pressure and high heart rate‡	14 (43.8%)	10 (32.3%)	0.66 (substantial; 10)	4.11 ± 1.04
27. Referred patient was an inpatient at the institution where your clinic resides	18 (69.2%)	12 (38.7%)	0.14 (low; 20)	-

CRT, Cardiac resynchronization therapy; HF, Heart failure; ICD, Implantable cardioverter-defibrillator; IV, Intravenous; NYHA class, New York Heart Association classification of HF.

‡criteria in clinical practice guideline.<sup>8,12,25,51,89</sup>

\*responses range from 1 “this should definitely not be considered” to 5 “this should definitely be considered” as an HF clinic inclusion or exclusion criterion. Mean and standard deviation shown.

||Cohen’s Kappa; Interpretation: values 0–0.20 none to slight concordance; 0.21–0.40 fair; 0.41– 0.60 moderate; 0.61–0.80 substantial concordance; and 0.81–1.00 almost perfect agreement<sup>121</sup>

§i.e., 1 is the highest level of agreement; ties are given the same rank.

Note: n and valid percentage shown to take into account any missing data, unless otherwise indicated.

-not assessed in referrer survey.

## CHAPTER FIVE

### EXTENDED RESULTS

This extended results chapter aimed to elaborate on the insights gained from the three studies (Chapters 2-4) presented earlier in this dissertation. Considering the feedback from the examination committee, a deeper understanding of the generalizability of the data, clarification of methodological choices, and the overall implications of study findings were discussed. Additionally, the strengths and limitations of the methodologies employed and the specific contexts that frame the rationale for this research to be performed in Ontario and Canada were expanded here.

One significant concern was regarding the generalizability of the data on HF clinic referrals to the broader population of Ontario and Canada. While the qualitative and quantitative findings provide significant insights, it is important to recognize that our sample populations for qualitative portion were specific to certain healthcare settings in Ontario, which may not reflect the entire province or the country considering various clinic setting (within hospital, stand alone, etc.) and reimbursement policy. In addition, representative generalizability is limited for respondents of the referring providers' survey as there are approximately 48,023 physicians, including specialty and 459,005 regulated nurse practitioners (although we do not know the specific number for cardiology practices) are currently working in Canada<sup>99,100</sup>, and we have secured 2325 email contacts irrespective of the identification of their sex to send the survey online, out of which only 73 completed the survey. It was not possible to identify the providers' sex from names, email addresses, and specialties. Thus, sex representativeness for the survey responders was limited.

With regard to HF clinic survey respondents, out of 128 identified clinics across Canada, 48 respondents completed the survey. Regarding representativeness by province for the clinic survey, 39% and 41% were from Ontario and British Columbia respectively. However, 11%,

25% and 33% from Quebec, New Brunswick and Saskatchewan respectively indicating that responses could be optimized if the survey was also available in French thereby limiting generalizability. Moreover, the demographic concentration of patient participants—primarily from urban areas served by established HF clinics—limits the representativeness of the findings in rural or underserved regions. Furthermore, the diversity in patient populations within Ontario requires careful consideration, as differences in socioeconomic status, ethnicity, and healthcare access could result in varying barriers to referral based on geographic and demographic factors. Future research should aim to expand the sample size and scope to include more diverse populations across Ontario and other provinces, enhancing our understanding of HF management in various contexts.

Another point raised was the absence of sample size calculation for the quantitative aspects of the studies. The decision not to specify a sample size stems from the exploratory nature of the research, which aimed to identify potential barriers and systemic issues in HF clinic referrals rather than provide definitive statistical inferences. Specifically, study 2 was a unique study and the first attempt to investigate referring providers' understanding of HF care in context to Canada. This study required specific, hard-to-reach population ---the referring providers and was impossible to ascertain whether or not a provider (eg. EM, NPs, FPs, GIM) refer to HF clinics, only by collecting email addresses. For example, out of 584 NPs email addresses collected 132 bounced back as invalid and only six completed the survey. Therefore, in-depth analysis of small sample could provide valuable understanding of complex interventions despite limiting generalizability. A similar approach was adopted for study 3, and sample size calculation was not performed as no statistical analysis was performed given the descriptive nature of the data. The areas of agreement between both parties were described quantitatively.

However, the survey ‘non-responders’ were defined as those who did not complete the surveys after receiving the invitation. The surveys were sent three times at an interval of four weeks to optimize the response rate. In addition, both the surveys were not focused to obtain baseline patient characteristics. One question for HFCs was whether or not having referral criteria stated explicitly on the clinic website vs not. However, from this data, it was impossible to interpret any difference in hard outcomes.

While the multimethod approach allowed for richer qualitative and quantitative explorations, it often limits the capacity to generalize findings beyond the sampled populations if the study involved complex intervention and access. Therefore, more rigorous follow-up studies utilizing power analysis and representative samples are essential to validate these findings and establish broader applicability. The Systematic Text Condensation method for qualitative analysis, drawn from common qualitative traditions, was selected for its robustness and accessibility. This method allows for rigorous thematic analysis while being manageable for novice researchers. It incorporates reflexivity and intersubjectivity, aligning well with the Andersen Framework for access to healthcare services. Additional clarity on the appropriateness of this method relative to others considered was elaborated under the specific study results. Focusing on the qualitative studies, the Andersen Framework provided a structured lens through which utilization of context-dependent healthcare interventions could be analyzed. The framework seeks to understand the dynamics of healthcare access, including predispositional factors, enabling and need factors by explaining questions like what works, what makes them work or not work, why and in which context.<sup>62</sup> Therefore, various qualitative techniques were employed—interviews and thematic analysis—allowing for differing perspectives to coalesce. Furthermore, the pilot testing of the interview guide enabled obtaining in-depth insights into care

providers' perspectives, which were crucial to interpreting such context-dependent mechanisms. The qualitative analysis through Systematic Text Condensation was a systematic way of simplifying, organizing, and condensing large amounts of text data to make it more manageable pieces of information in a summarized version. The strengths of such an approach lie in its ability to distill rich, nuanced experiences into identifiable themes, while weaknesses could include potential bias in thematic interpretation and generalizability, which was discussed transparently in this section.

### *Findings by Study:*

#### *Study 1: Factors Affecting Patient Access to HF Clinics*

From interviews conducted with stakeholders in Study 1, it became clear that many clinic providers and policymakers perceived that there were inefficiencies in receiving appropriate referrals due to a lack of organization and clinic' standardization across the province. For example, some respondents highlighted that they were not receiving the patients who needed the care most, indicating gaps in understanding of which patients should be prioritized for HF clinic services. The themes emerging from these interviews identified the importance of explicit statements on clinic entry (referral) criteria, clarity on the clinic purpose (i.e., target population), and specific discharge criteria to ensure a smooth transition to the community for various stable patients who do not fulfill the criteria for complex cardiac interventions (i.e., advanced therapy, transplant) except the need to continue regular follow up. This will also assist clinics to accommodate new HF patients. Future studies should focus on clarifying appropriate referrals from various HF clinics, both tertiary and community-based, and how these referrals impact patient outcomes. Moreover, considering the diversity within Ontario, this study highlighted the challenges clinics faced in accommodating patients with varying needs based on their socio-

demographics and disease phenotypes. The findings also stressed the importance of addressing potential technological barriers among patients, particularly older patients who may require family support to navigate virtual health appointments. Future studies should evaluate how patient age demographics influence referral practices and clinic attendance.

### *Study 2: Referring Provider Perspectives*

For the study 2, the referring provider's interview guide was pilot-tested before starting the project to ensure capturing the detailed insights and the overlapping themes that might be revealed from the qualitative analysis. The perspective of healthcare providers regarding their referral practices revealed significant disparities based on their clinical expertise, scope, and patient characteristics. The implications of these disparities, particularly around the under-referral of older female patients with HF and those with preserved ejection fraction, warrant further investigation into systemic biases that may impede appropriate care. The variability in responses to this cross-Canada survey also raised questions about the representativeness of findings, with notably different response rates across provinces. In addition, regarding the concern about the "not applicable" option for referring providers' survey in Table 10, it was given the option to check for each attitudinal item along with the 5-point Likert scale. The number of respondents who checked the "not applicable" response was not the same for each item, indicating that respondents were from diverse clinical expertise. Therefore, inapplicability varies per attitudinal item in the survey. Future research focusing on more detailed demographic analysis may contribute to understanding the trends and their implications for equitable care across Canada.

### *Study 3: Ideal Inclusion and Exclusion Criteria*

Identifying the ideal HF clinic inclusion and exclusion criteria in study 3 underscored the pressing need for standardization across clinics. This standardization if implemented, could address the variability in practice that currently leads to inequitable access. The study highlighted the commonly accepted HF referral criteria consistent with guidelines, while also revealing some additional factors stressed by HF referrers that clinics do not equally practice.<sup>122</sup> The results suggested that actively publicizing clinic criteria could foster transparency and streamline referrals. Moreover, the study emphasized the importance of considering potential strategies for implementing such changes within the complex landscape of healthcare policy, providing a roadmap for future improvements in HF management.

While this dissertation has presented a critical understanding of HF clinic referrals and utilization patterns, it also highlights the potential for positive changes. Limitations persisted in response biases, potential over-representation of specific demographics, and methodological constraints in qualitative analysis. The variations in provider responses and the underrepresentation of specific populations underscore the need for further research—particularly in rural settings—where disparities may be even more pronounced. Future research should strive towards extensive quantitative studies with adequate representative sample of diverse clinical phenotypes and robust participatory approaches to enhance engagement from various stakeholder groups. Addressing these knowledge gaps regarding access barriers and inequities is crucial, as this will provide more comprehensive policy implications and guide future interventions aimed at improving HF patient outcomes.

Overall, this dissertation's results elucidated the multifaceted dimensions of HF clinic utilization and the barriers encountered within the referral pathway. The aim was to make

valuable contributions to the understanding of HF management and improve access to essential care for affected patients across Ontario and beyond. Continued exploration of these dynamics will be integral in shaping the future landscape of HF management in healthcare systems.

## CHAPTER SIX

### INTEGRATIVE DISCUSSION

Based on clinical practice guideline recommendations,<sup>12,13,25</sup> all eligible HF patients should be referred to appropriate HF clinic services. However, it is crucial to note that referral alone does not guarantee access, as various barriers exist at the health system and patient levels. Through the three interlinked studies presented in this dissertation, key factors hindering the optimal utilization of HF clinics were identified, and potential solutions were proposed.

In the first study, findings from the qualitative research suggested that enhancing access to clinics could be achieved by addressing issues such as limited number of clinics, limited clinic capacity, lack of standard discharge criteria to make rooms for new patients, and the discordance between clinic entry criteria (i.e., inclusion, exclusion criteria) and lack of regional coordination. It is also suggested that a re-evaluation of clinic criteria is necessary, with transparent posting of these criteria. To increase appropriate HF clinic referrals, clinics should actively communicate their entry criteria to referring providers within their catchment area. However, additional research is needed to thoroughly examine the actual effects of implementing these strategies.

The second study investigated factors impeding appropriate provider referral to HF clinics. Results highlighted the need for greater provider knowledge about clinics, and support for patient communication and the referral process. Legitimate barriers, such as clinic-to-clinic service variations, a lack of clarity in clinic-specific inclusion criteria, and prolonged wait times, were identified. Results stress the importance of implementing a regional model across the continuum of care such as, CorHealth's.<sup>6</sup>

Finally, the third study examined the clinics' and referrers' perspectives based on various international guideline recommendations to determine optimal criteria for entry into HF clinics. It was found that there is considerable agreement between clinics and referrers for selected clinic entry criteria, which are also recommended in the guidelines. However, referrers also highlighted

some other criteria from guidelines, which were not equally voted on by the clinics, indicating the necessity to update the policies according to disease severity and patient needs. Therefore, results suggested implementing varying levels of clinics based on disease complexity within a coordinated system as suggested in CorHealth's model.

#### *Andersen's Behavioral Model Application for HF Clinic Utilization*

Healthcare utilization is the point on the healthcare continuum where patients' needs intersect with the healthcare system organization. Various impediments can prevent or limit the use of HF clinics, including varied patient characteristics leading to individual patient-centered care. Andersen's Behavioral Model proposes that healthcare utilization is influenced by multiple factors<sup>61</sup>. This dissertation encompassed two of three predisposing factors at the contextual level of this model: predisposing and need factors.

Regarding the former, as per our equity focus, study 1 identified factors intervening in the appropriate referral and access to HF clinics, namely, limited human resources, insufficient capacity, undefined discharge criteria, or the complex nature of the disease requiring multiple continuous healthcare touchpoints. However, this aligned with the factors influencing one's predisposition to use healthcare resources mentioned in Chapter 1.

Regarding need factors, the providers perceived the need for an HF clinic, considering that eligible HF patients must be referred to outpatient HF clinic services and could benefit from such services (i.e., referring physician's endorsement and knowledge is an essential predictor of accessing outpatient HF clinic services). Previously published research also showed an increased healthcare utilization of those who receive correct health information about their condition from their providers and are empowered with informed decision-making.

### *Knowledge Translation*

It is evident that generating new knowledge alone is not sufficient unless it is disseminated to the targeted audiences to ensure broad implementation and positive impacts on health. Therefore, the findings in this dissertation were strategically planned for translation into practice through knowledge translation (KT) activities. The candidate undertook various knowledge mobilization approaches for academic target audiences; upon publication of the studies, practical synopses were circulated via social media platforms, including the patient partner organization. In addition, results were presented at various national and international conferences for dissemination to HF clinics and other care providers, namely, Ted Rogers Heart Failure Symposium, October 2023, International Conference on Aging, Innovation, and Rehabilitation (ICAIR), May 2023, and 9<sup>th</sup> Asian Preventive Cardiology & Cardiac Rehabilitation Conference Hong Kong, China, November 2022 (Hybrid).

### *Future Directions*

The three studies included in this dissertation suggest that, improved clarity and coordinated communications are pivotal for ensuring appropriate HF clinic utilization. However, implementing CorHealth's regional care model, coupled with the integration of virtual care opportunities, has the potential to address inequities faced by older, frail, and remote patients in accessing such services. Moreover, future research could explore whether developing an innovative co-designed model of HF clinic care could ensure the quality and transparency in HF clinic access. This could also promote reaching the right patient who needs the care most at the right time. However, such interventions should be standardized for testing in real-world practice with barriers to utilization in mind. Additionally, these models' beneficial and unintended effects should be studied within the context of the costs and resources they require.

Future research is needed to establish and implement a coordinated care model to determine whether it can avert hospital readmission—an HF care quality indicator. Another viable avenue involves including HF in nursing training curricula, which could enhance the capacity of the specialized workforce. Furthermore, future studies collaborating with international stakeholders to explore the patient characteristics and regional program variations could inform policy decisions on the practices, ultimately contributing to the optimal utilization of HF clinic services.

Another important aspect would be to effectively address the needs and preferences of ethnocultural minorities and LGBTQ+ groups in future HF care. It is essential to adopt a multifaceted approach that recognizes the unique challenges these populations face. First, conducting targeted research to better understand the specific barriers to access and care that ethnocultural minorities and other groups encounter, such as socioeconomic factors, cultural beliefs, language differences, and social stigma, will be crucial. This can inform the development of culturally tailored interventions that resonate with diverse communities. Moreover, engaging community stakeholders and leaders in the design and implementation of HF clinic services can enhance trust and facilitate outreach efforts. Providing training for healthcare providers on culturally competent care will also help address biases and improve communication with patients from minority backgrounds. Incorporating patient education programs sensitive to cultural contexts can empower these groups to navigate HF management more effectively. Lastly, efforts should be made to ensure that HF clinics are located in accessible areas, with consideration for transportation and financial barriers that disproportionately affect minority populations. By prioritizing inclusivity and equity in HF care, healthcare systems can ensure that all patients receive the support and resources necessary to manage their condition successfully.

Overall, the broader impact of this dissertation on enhancing access to HF clinics extends beyond individual patient outcomes to significant implications for health policy and practice. By addressing the barriers to referral and access for HF patients, healthcare systems can reduce hospital readmission rates and associated healthcare costs, as studies indicate that timely intervention within HF clinics can decrease HF-related hospitalizations by as much as 56%<sup>3,72</sup>. Policymakers should prioritize the development of comprehensive referral pathways and integrate HF clinic services into primary care frameworks, ensuring that providers and patients are aware of available resources. Additionally, tailoring educational initiatives for healthcare providers can help challenge existing beliefs and biases regarding HF management, thus improving referral rates. The incorporation of multidisciplinary teams within HF clinics aligns with best clinical practices. It promotes a patient-centered approach that empowers individuals with the knowledge and skills necessary for effective self-management. Fostering a systematic transformation in HF care delivery can lead to improved health outcomes, reduced healthcare expenditures, and an overall advancement in the quality of care for one of the most pressing chronic conditions facing populations globally.

## CONCLUSIONS

Despite the established benefits of HF clinics, existing scientific evidence investigating gaps in provider referral and patient access to HF clinics is limited. This dissertation is pivotal in identifying barriers and facilitators related to referral and access to specialized HF clinic services, offering insights from different stakeholders' perspectives. Based on current practices, guidelines need to be updated on which patients are ideally suited for HF clinic services. Since they often lack specificity, exhibit discordance and face challenges in practical implementation

across patient-to-system levels. Overall, the findings herein can guide policymakers, healthcare providers, and HF patients towards appropriate utilization of HF clinic services and, ultimately, reduce HF-related mortality and hospital readmissions. Future research is needed to measure the effectiveness of consistently implementing evidence-based guidelines to determine the appropriate patients accessing HF clinics with the best times to intervene based on their disease complexity. This way, timely accessibility to these services could benefit patients and providers. Furthermore, future research should also focus on evaluating the impact of innovative strategies like a coordinated care model aimed at optimal access to understand patient and provider experiences in-depth while in HF clinic care.

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## APPENDICES

### APPENDIX A EXPERT ADVISORY COMMITTEE

1. **Dr. Luisine Abrahamyan MD, PhD, Expert on HF Research**, Assistant Professor, Toronto Health Economics and Technology Assessment (THETA), University of Toronto.
2. **Dr. Michael McDonald MD, Representative of Ontario HF clinic provider**, Assistant Professor of Medicine, University of Toronto, Director, Ted Rogers Centre, Toronto.
3. **Dr. Douglas Lee MD, PhD, FRCPC, Expertise in HF epidemiology and outcomes, Representative of Ontario HF clinic referrer**, Professor of Medicine, University of Toronto, Senior Scientist, Toronto General Hospital Research Institute (TGHRI), Toronto.
4. **Dr. Karen Harkness PhD, Representative of Ontario HF policy maker**, Clinical Strategist, CorHealth Ontario, Assistant Clinical Professor, Faculty of Health Sciences, McMaster University, Hamilton.
5. **Dr. Sean Virani MD, MPH, FRCPC, Non-Ontario expert / Canadian Heart Failure Society Board Representative and HF patient partner**, Associate Professor, University of British Columbia, BC. Medical Director, HeartLife Foundation, Canada.

## **APPENDIX B: INTERVIEW GUIDES FOR ALL STAKEHOLDER GROUPS (STUDY - 1)**

### **I. SEMI-STRUCTURED INTERVIEW GUIDES- FOR PATIENTS**

#### **Introduction:**

Good day! Thank you for volunteering to participate in this interview. My name is Taslima, a doctoral student at York University. You have been asked to participate in this discussion because your point of view is important to us. I realize you are busy and I appreciate your time. This interview aims to gather your thoughts regarding the utilization of heart function (HF) clinics, including factors that influence the process of referrals. I realize COVID-19 has impacted HF clinic access, so we will touch on that too.

**Did you have a chance to look over the consent form I sent?** The interview will take about 30 minutes. If there are any questions that you do not wish to answer, you do not have to do so; however please try to answer and be as open as possible.

Data storage: Video-recordings will be kept safely on a secure hospital server until they are transcribed word for word, then they will be destroyed. Interview audio-recordings, notes and transcripts of the interview will contain no information that would allow individual subjects to be linked to specific statements. These will also be stored securely, but using a research number only.

Do you have any other questions about the study or consent form? (answer any questions) If you feel willing to undertake the interview can you please sign and email me back the consent form? May I begin the recording of the discussion to facilitate its recollection?

#### **Interview Questions**

1. Let's just start with a few questions about you if you are willing to provide that for context.
  - a. Sociodemographic
    - i. Age, sex, size of area lived in [urban, suburban, rural]?
  - b. Clinical:
    - i. Do you know what type of HF you have, or approximately what is your ejection fraction?
      1. e.g., HFpEF or HFrEF
    - ii. How long have you had it?
    - iii. Have you gone to the emergency department for your HF?
2. How would you describe a heart function clinic?
  - a. PROBE
3. Could you describe your experience with being referred to a heart function clinic?
  - a. What did you remember about it?
  - b. Where were you? Were loved ones present?
  - c. Who told you about the referral?
    - i. Doctor, nurse...
  - d. Did they tell you why you were being referred?
    - i. If yes, what did they tell you?
  - e. Were you provided any pamphlets to take home about the clinic or referral?
  - f. Did they tell you the next steps like whether you should call the clinic and the number or when to expect a call from the clinic?
  - g. What do you think worked well? What didn't work well?
4. Do you think there is anything your healthcare providers could have done to make it easier to access the HF clinic?
  - a. Please describe.
5. Do you think your doctor provided you with enough information to know what you were being referred for and why?
  - a. If not, what else did you want to know?
6. Did you actually go to the HF clinic?

If yes:

- Did you face any barriers going to the heart function clinic? If yes, could you please describe?
- Are there any factors or actions that were taken by the doctor that helped facilitate the transitioning to the specialist clinic?
- Were you provided with adequate information before your appointment to prepare you for your visit at the HF clinic?
- Did the clinic provide you with a time and date that was convenient for you?
- Did you go more than once?

- a. Did ever miss an appointment at the HF clinic? What was the reason?

If no:

- Are there any personal factors (e.g. financial, family, health (comorbidities) etc.) that made it difficult for you to attend the specialist clinic?
    - a. PROBE Parking costs, transportation, distance, any other issue.
7. Please share any final comments related to your overall experience with the referral system that we may have missed.

## II. SEMI-STRUCTURED INTERVIEW GUIDES- FOR HF CLINIC REFERRERS

### **Introduction:**

Good day! Thank you for volunteering to participate in this interview. My name is Taslima, a doctoral student at York University. You have been asked to participate in this discussion because your point of view is important to us. I realize you are busy and I appreciate your time. This interview aims to gather your thoughts regarding the utilization of heart function (HF) clinics, including factors that influence the process of referrals. I realize COVID-19 has impacted HF clinic access, so we will touch on that too.

**Did you have a chance to look over the consent form I sent?** The interview will take about 30 minutes. If there are any questions that you do not wish to answer, you do not have to do so; however please try to answer and be as open as possible.

Data storage: Video-recordings will be kept safely on a secure hospital server until they are transcribed word for word, then they will be destroyed. Interview audio-recordings, notes and transcripts of the interview will contain no information that would allow individual subjects to be linked to specific statements. These will also be stored securely, but using a research number only.

Do you have any other questions about the study or consent form? (answer any questions) If you feel willing to undertake the interview can you please sign and email me back the consent form?

May I begin the recording of the discussion to facilitate its recollection?

### **Interview questions**

Let's just start with a few questions about your role if you are willing to provide that for context.

- a. What is your clinical specialty?
- b. Do you work in an academic institution? If yes

- i. Does this institution have an HF clinic?
2. What type of patients do you think should be referred to an HF clinic?
  - a. Does this differ do you think from the patients who you typically refer?
3. Do you know of guidelines regarding which patients should be referred to HF clinics?
  - a. Which ones? What do they suggest?
4. Do you refer your patients to HF clinics?
  - a. Why or why not?
  - b. How many HF clinics are you aware of in your area?
5. Do you perceive HF clinics are beneficial for appropriate patients?
  - a. Do you think the HF clinics closest to where you practice are of good quality? (if applicable – i.e., they have clinics in proximity)
    - i. How do you think it could be improved?
6. How often would you say you refer patients to HF clinics?
  - a. What proportion of your indicated HF patients would you say you refer to an HF clinic?
  - b. What are the reasons for this?
7. Who is typically responsible for making HF clinic referrals in the hospital?
  - a. What type of training do these individuals receive to make referrals?
  - b. Do other staff members support the referral process?
8. Could you please describe the procedure used to consider referring patients?
  - a. Are there any specific clinical criteria or checklists used?
9. When making referrals, are there any non-clinical factors considered (e.g. willingness to participate, demographic factors etc.)?
  - a. Please describe.
10. How do you refer?
  - a. Paperwork to complete; mode of submission to the clinic (e.g., fax)
  - b. Who, if anyone, discusses the referral with the patient?
    - i. What do they/you typically tell a patient?
    - ii. What if the patient is too ill or otherwise unable to consider referral during your patient-provider encounter?
    - iii. What is usually the course of action for patients who you want to refer but tell you they do not want to go?
      1. E.g., What happens to patients who might need to be referred but cannot get there due to distance or lack of transportation?
11. What happens after the referral is sent?
  - a. Does your clinic follow-up with the patients after they have been referred to determine whether or not the referral was accepted?
    - i. If so, who is responsible for this?

- b. Is there a system in place in your organization to track / audit how many patients who have been referred and whether the appropriate patients are referred?
- 12. What barriers have you faced when making referrals for your patients?
  - a. Any facilitators?
- 13. On a system-wide level, are there any policy, organizational or financial barriers that might affect the referral process?
  - a. Could you tell me what these factors are?
  - b. Any facilitators?
- 14. COVID-19 has greatly impacted acute and chronic care. In what ways do you perceive it has hindered HF clinic access for patients?
- 15. What final suggestions do you have for improving the referral system or appropriate access to HF clinics for patients that we haven't considered?

### III. SEMI-STRUCTURED INTERVIEW GUIDES- FOR HF CLINIC SERVICE PROVIDERS

#### **Introduction:**

Good day! Thank you for volunteering to participate in this interview. My name is Taslima, a doctoral student at York University. You have been asked to participate in this discussion because your point of view is important to us. I realize you are busy and I appreciate your time. This interview aims to gather your thoughts regarding the utilization of heart function (HF) clinics, including factors that influence the process of referrals. I realize COVID-19 has impacted HF clinic access, so we will touch on that too.

**Did you have a chance to look over the consent form I sent?** The interview will take about 30 minutes. If there are any questions that you do not wish to answer, you do not have to do so; however please try to answer and be as open as possible.

Data storage: Video-recordings will be kept safely on a secure hospital server until they are transcribed word for word, then they will be destroyed. Interview audio-recordings, notes and transcripts of the interview will contain no information that would allow individual subjects to be linked to specific statements. These will also be stored securely, but using a research number only.

Do you have any other questions about the study or consent form? (answer any questions) If you feel willing to undertake the interview can you please sign and email me back the consent form?

May I begin the recording of the discussion to facilitate its recollection?

#### **Interview questions (Heart failure clinics)**

1. Let's just start with a few questions about your role if you are willing to provide that for context.

- What is your profession?
  - How long have you worked at the HF clinic?
  - Where is your clinic located? (ie..., tertiary care ctr, community)
  - How many staff work at the clinic?
  - How many pts do you estimate you treat / year?
2. What do you think are the mechanisms or processes by which patients are referred to your clinic? Please describe.
  3. In your opinion, do you think the referrers do a good job at referring patients to your clinic?
    - Appropriate patients (e.g., acuity), timeliness
    - Are there patients you think you should be seeing but do not get referred for instance?
  4. What do you do with referrals that are inappropriate / do not meet your referral or inclusion criteria?
    - Probe: communication with referring doc, other docs in circle of care, patients
  5. COVID-19 has greatly impacted acute and chronic care. In what ways do you perceive it has hindered and / or facilitated HF clinic access for patients?
    - PROBE: faster implementation of remote care technologies to support patient care in the community
  6. For patients who do not show at their initial or miss appointments, what are some common reason why they are unable to attend?
  7. What policies or organizational-related factors negatively affect patient referrals and access to your clinic? Please describe
  8. What barriers have you encountered in receiving patient referrals?
    - Any facilitators?
  9. Do you have any final suggestions for improving the referral system or access for appropriate patients that we haven't discussed?

#### IV. SEMI-STRUCTURED INTERVIEW GUIDES- FOR POLICYMAKERS/ ADMINSTRATORS

##### **Introduction:**

Good day! Thank you for volunteering to participate in this interview. My name is Taslima, a doctoral student at York University. You have been asked to participate in this discussion because your point of view is important to us. I realize you are busy and I appreciate your time. This interview aims to gather your thoughts regarding the utilization of heart function (HF) clinics, including factors that influence the process of referrals. I realize COVID-19 has impacted HF clinic access, so we will touch on that too.

**Did you have a chance to look over the consent form I sent?** The interview will take about 30 minutes. If there are any questions that you do not wish to answer, you do not have to do so; however please try to answer and be as open as possible.

Data storage: Video-recordings will be kept safely on a secure hospital server until they are transcribed word for word, then they will be destroyed. Interview audio-recordings, notes and transcripts of the interview will contain no information that would allow individual subjects to be linked to specific statements. These will also be stored securely, but using a research number only.

Do you have any other questions about the study or consent form? (answer any questions) If you feel willing to undertake the interview can you please sign and email me back the consent form?

May I begin the recording of the discussion to facilitate its recollection?

##### **Interview questions (Policymakers/Administrators)**

1. Let's just start with a few questions about your role if you are willing to provide that for context.

- a. What is your jurisdiction in terms of cardiac care (institution(s), province...)
- b. Tell me about your position and what you do in relation to HF clinics
- c. What is your education / training background?
- d. How long have you worked in heart policy /practice? (years)
2. What policies has your organization created or are planning to create regarding HF clinics and outpatient HF care?
  - a. Does your organization work from association or other organization's policies on HF clinics? If yes, which ones?
3. What is the current status of HF clinics in your jurisdiction from a system perspective?
  - a. Number, who should access ...
4. When thinking about HF care, what role does your organization envision for HF clinics?
  - a. Is this different than current reality?
5. In your jurisdiction, do you think the appropriate patients access HF clinics?
  - a. Why or why not?
    - i. Who should access them less vs more?
6. What kinds of policies / tools do you think are needed to optimize use of HF clinics in your jurisdiction?
  - a. e.g., toolkits/protocols/checklists aimed at standardizing the referral process for all clinics?
  - b. policies aimed at improving referral rates to heart failure clinics?
  - c. Tracking and feedback to EDs?
7. Do you have any departments/teams or committees/ working groups focused on HF clinics in your organization?
  - a. Are there regular opportunities to discuss HF clinic organization and performance in your jurisdiction?
    - i. What are they? Who sits at these tables? What is generally discussed?
      1. Is there enough time and energy do you think to consider the organization of HF clinics and their role in the outpatient care journey?
8. COVID-19 has greatly impacted acute and chronic care. In what ways do you perceive it has hindered and / or facilitated HF clinic utilization?
9. Do you have any final suggestions on how access and referral to HF clinics could be optimized that we haven't covered?

## APPENDIX C: SURVEY OF HEART FAILURE PATIENT REFERRERS TO

### UNDERSTAND FACTORS INFLUENCING HF CLINIC REFERRALS (STUDY - 2)

The survey consists of: (1) a few questions related to your occupational practice, then (2) some attitudinal items, (3) your views on criteria regarding which patients should be referred to HF clinics, (4) items related to COVID-19, and finally (3) two brief case scenario.

1. Please indicate your sex:  
 Male  Female  Other/prefer not to answer
  
2. Please tell us your primary specialty:  
 Family/Primary Care Medicine  
 Internal Medicine  
 Cardiology  
 Emergency Medicine  
 Other, please specify: \_\_\_\_\_  
\_\_\_\_\_
  
3. What is your profession?  
 Doctor  
 Nurse-Practitioner
  
4. How many years have you been practiced? \_\_\_\_\_ years (in HF clinics or overall)?
  
5. In what type of institution do you practice?  
 hospital  outpatient only
  
6. Is the organization where you practice an academic one?  
 Academic  Non-academic
  
7. Does the institution where you work have an HF clinic?  
 Yes  No

8. In which province / territory do you practice (Canada)? \_\_\_\_\_

9. Which clinics do you refer to? (This question is optional. We are also surveying clinics. If you share with us the clinic names [email addresses would help too] we can ensure we get a representative sample of responses):

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**BLOCK I: HCP’S KNOWLEDGE ON REFERRAL TO HF CLINICS**

Please indicate how much you agree or disagree with the following statements regarding referral to heart failure (HF) clinics	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
1. I only refer certain types of my HF patients to clinics.	<input type="checkbox"/>					
2. I am more inclined to refer my patients with systolic dysfunction.	<input type="checkbox"/>					
3. HF guidelines in Canada are clear on referring patients to HF clinics.	<input type="checkbox"/>					
4. I find referral to HF clinics is particularly valuable for my complex patients (e.g., multimorbidity)	<input type="checkbox"/>					
5. The criteria for referral to HF clinics is very clear to me	<input type="checkbox"/>					
6. I always refer my HF patients who meet the clinic referral criteria	<input type="checkbox"/>					
7. I do not always refer patients who meet the referral criteria, because there are not enough HF clinics	<input type="checkbox"/>					

8.	There are processes within our practice setting to automatically trigger an HF clinic referral when it is indicated	<input type="checkbox"/>					
9.	There are processes within our practice setting to support HF clinic referral completion and submission	<input type="checkbox"/>					
10.	I am not familiar with HF clinic sites outside my geographic area, so cannot readily refer my appropriate patients who come from afar.	<input type="checkbox"/>					
11.	Variation in inclusion / exclusion policies across clinics renders it difficult to refer appropriate patients	<input type="checkbox"/>					
12.	The evidence of benefit of HF clinics is very strong.	<input type="checkbox"/>					
13.	I refer most of my HF patients to cardiac rehabilitation	<input type="checkbox"/>					
14.	All high-risk HF patients should be managed in specialized, multi-disciplinary clinics	<input type="checkbox"/>					

BLOCK II: HCP'S PERCEPTION ON REFERRAL TO HF CLINICS

<b>Please indicate how much you agree or disagree with the following statements regarding referral to heart failure (HF) clinics</b>		<b>Strongly Agree</b>	<b>Agree</b>	<b>Neutral</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>N/A</b>
15.	My colleagues generally refer their appropriate patients to HF clinics.	<input type="checkbox"/>					
16.	Attendings are somewhat hesitant to refer patients to HF clinics.	<input type="checkbox"/>					
17.	Primary care providers should be referring to HF clinics.	<input type="checkbox"/>					

18.	Patients seem to have so many barriers to going to HF clinics.	<input type="checkbox"/>					
19.	I only refer my high-risk patients to HF clinics.	<input type="checkbox"/>					
20.	I only refer my patients who have been to the emergency department to an HF clinic	<input type="checkbox"/>					
21.	Having HF clinics as part of the continuum of care for HF patients can often complicate care coordination	<input type="checkbox"/>					
22.	I believe I am better equipped to handle my HF patients than HF clinics	<input type="checkbox"/>					
23.	I will not refer a patient if I believe the patient will not follow through with the referral	<input type="checkbox"/>					
24.	There is likely some unconscious bias in referral of patients to HF clinics at our organization (e.g., sex bias, ethnicity bias, socioeconomic status)	<input type="checkbox"/>					

### BLOCK III: HCP'S ATTITUDE ON REFERRAL TO HF CLINICS

Please indicate how much you agree or disagree with the following statements regarding referral to heart failure (HF) clinics		Strongly	Agree	Neutral	Disagree	Strongly	N/A
		Agree	Disagree	Strongly	Disagree	N/A	
25.	There is so much variation in HF clinics, it is difficult to be certain what each one has to offer or delivers.	<input type="checkbox"/>					
26.	The wait times for patients to get in to the HF clinic are too long.	<input type="checkbox"/>					
27.	We offer multi-disciplinary, chronic care in our practice, so referral to an HF clinic is unnecessary	<input type="checkbox"/>					

28.	HF clinics are very valuable for addressing end-of-life issues with my HF patients	<input type="checkbox"/>					
29.	Reimbursement policies are a financial disincentive to HF clinic referral	<input type="checkbox"/>					
30.	I do not always refer patients who meet the referral criteria, as sometimes they report barriers to attending, such as lack of transportation	<input type="checkbox"/>					
31.	Some of my patients would benefit from HF clinics, but there are no clinics within their geographical area, so I cannot refer them	<input type="checkbox"/>					
32.	Patient preferences are considered when making referral decisions	<input type="checkbox"/>					
33.	I am skeptical about the benefits of HF clinics	<input type="checkbox"/>					
34.	My patients have had a bad experience with a HF clinic	<input type="checkbox"/>					
35.	I am satisfied with the communication from the HF clinic summarizing the patient care which they provided	<input type="checkbox"/>					

**36.** Please list other important factors that affect your referral of patients to HF clinics:

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BLOCK IV: HF CLINIC REFERRAL CRITERIA BASED ON GUIDELINES

RECOMMENDATIONS

How important are the below factors in determining which patients should be referred to an HF clinic?	This should definitely not be considered	This should not be considered	Neutral	This should be considered	This should definitely be considered
1. Diagnosis of heart failure with preserved ejection fraction (HFpEF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Diagnosis of heart failure with reduced ejection fraction (HFrEF)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. 1 Emergency department visit due to HF in the last 3 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. 2 of more ED visits for HF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Recent hospitalization due to HF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. 2 or more hospitalizations due to HF	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Medications need titration, changes are required for optimization, or there may be interactions with other medications patients are taking, and you need some consulting advice (sub-optimal drug therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Progressive intolerance or down-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

titration of medications needed					
9. Patient visiting general cardiologist, internist or primary care provider with complaints of persistent shortness of breath	<input type="checkbox"/>				
10. Stage D HF (i.e., advanced, end-stage HF)	<input type="checkbox"/>				
11. IV inotropes	<input type="checkbox"/>				
12. NYHA Class IIIB/IV symptoms	<input type="checkbox"/>				
13. Persistently-elevated natriuretic peptides	<input type="checkbox"/>				
14. HF is secondary to congenital heart disease or pulmonary hypertension	<input type="checkbox"/>				
15. New diagnosis HF	<input type="checkbox"/>				
16. HF patient requires rhythm device (ICD, CRT)	<input type="checkbox"/>				
17. Recurrent defibrillator shocks	<input type="checkbox"/>				
18. Cardiac transplantation consideration	<input type="checkbox"/>				
19. You perceive the patient is at risk of hospital admission	<input type="checkbox"/>				
20. Patient has barriers to behaviour change; needs	<input type="checkbox"/>				

education and coaching to support self-management					
21. Comorbidities causing complexity in treatment approach	<input type="checkbox"/>				
22. Amyloidosis	<input type="checkbox"/>				
23. Genetic cardiomyopathies	<input type="checkbox"/>				
24. End-organ dysfunction/ worsening renal or liver function related to HFHF	<input type="checkbox"/>				
25. Edema despite escalating diuretics	<input type="checkbox"/>				
26. Low blood pressure and high heart rate	<input type="checkbox"/>				
27. Other, please specify: _____ _____					

1. Has COVID-19 impacted your referral of patients to HF clinics?

Yes

No

1b. if yes, in what ways? (check all that apply)

I am more likely to refer as I know some of the clinics have technology to better monitor patients remotely, thus reducing physical contact within the healthcare system

I am less likely to refer as I am unsure how they would safely take on new patients given attempts to limit in-person patient care

I am consulting with patients more regarding whether they feel safe being referred

Other (please specify:

\_\_\_\_\_)

2. Have HF clinics where you refer patients been in communication with you regarding any changes in care access or referrals given COVID-19?

Yes

No

2b. if yes, what did they communicate?

\_\_\_\_\_

3. What has changed regarding support for higher-risk HF patients in terms of accessible community care due to COVID in your experience?

4. Do you perceive your patients would be able to have virtual specialty HF outpatient care visits? (check all that apply)

Yes, mostly

Quite a few patients have no internet access, but could do phone visits

Quite a few patients have unreliable or slow internet access

Quite a few patients do not have sufficient technological skills to do a virtual care visit, without assistance

Quite a few patients do not have sufficient language or cognitive abilities to do a virtual care visit

Other (please specify: \_\_\_\_\_)

**Case Scenario 1 of 2:** You have a 75-year old female patient who has been previously diagnosed with HFpEF and has had a hospital visit related to her heart failure diagnosis this year. She is struggling with worsening edema that limits her mobility and her creatinine has fluctuated with changes in her loop diuretic. Her baseline creatinine is 130  $\mu\text{mol/L}$ , but had risen up to 200  $\mu\text{mol/L}$  earlier this year when her furosemide dose was increased.

1. Would you refer this patient to an HF clinic?

Yes  No

2. Why or why not? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Case Scenario 2 of 2:** You have a 57 year old male patient who had an anterior wall myocardial infarction several years ago. His LV ejection fraction is 35% and he reports NYHA class II symptoms. He has had difficulty tolerating up-titration of his ACE inhibitor due to relatively low blood pressure. His latest BP reading is 105/60.

3. Would you refer this patient to an HF clinic?

Yes  No

4. Why or why not? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

THANK YOU

**APPENDIX D: SURVEY OF HF CLINIC PROVIDERS ON INCLUSION/ EXCLUSION**

CRITERIA (STUDY - 3)

**HF Clinic Inclusion / Exclusion Criteria Survey**

First we would like to know a little about your clinic.

- A. Province: \_\_\_\_\_
- B. How is your HF clinic staffed? (check one)
- Single generalist provider
  - Single HF expert provider
  - Multiple providers
- C. Please check off all the following elements / aspects that are part of your HF clinic:
- Patient education to promote self-care
  - Medication titration
  - Supervised exercise
  - Other (please specify: \_\_\_\_\_)
- D. What is the typical duration that a patient will be in your program (you can use .5 etc to denote weeks)? \_\_\_\_\_ months
- E. On average, how many in-person contacts do you have with each patient?  
\_\_\_\_\_ visits
- F. In what kind of institution does your clinic reside?
- Tertiary / quaternary hospital
  - Community hospital
  - Primary care
  - Other (please specify: \_\_\_\_\_)
- G. Does your clinic treat non-HF patients?
- Yes
  - No

H. Please Note that the criteria listed in the table below have been developed based on the best practices and the guidelines recommendations. Therefore, please complete the table denoting whether each factor is **both** an inclusion or exclusion criterion for your clinic. “Yes” means it is considered a criterion so patients are vetted against the factor, and “no” means it is not considered in decisions regarding who is eligible to receive care at the clinic. There is a space to report “other” criterion at the bottom. Also denote to the right for each whether you agree or disagree that the factor should be a criterion for patients to access HF clinics.

CRITERION	INCLUSION at your clinic	EXCLUSION at your clinic	SHOULD BE A CRITERION?
1. Diagnosis of heart failure with preserved ejection fraction (HFpEF)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
2. Diagnosis of heart failure with reduced ejection fraction (HFrEF)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
3. 1 Emergency department visit due to HF in the last 3 months	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
4. 2 of more ED visits for HF	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion

			<input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
5. Recent hospitalization due to HF	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
6. 2 or more hospitalizations due to HF	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
7. Medications need titration, changes are required for optimization, or there may be interactions with other medications patients are taking, and you need some consulting advice (sub-optimal drug therapy)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
8. Progressive intolerance or down-titration of medications needed	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic

9. Patient visiting general cardiologist, internist, or primary care provider with complaints of persistent shortness of breath, even at rest	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
10. Stage D HF (i.e., advanced, end-stage HF)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
11. IV inotropes	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
12. NYHA Class IIIB/IV symptoms	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
13. Persistently-elevated natriuretic peptides	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
14. HF is secondary to congenital heart disease or pulmonary hypertension	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
15. New diagnosis HF	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion

			<input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
16. HF patient requires rhythm device (ICD, CRT)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
17. Recurrent defibrillator shocks	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
18. Cardiac transplantation consideration	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
19. You perceive the patient is at risk of hospital admission	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
20. Patient has barriers to behaviour change; needs education and coaching to support self-management	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
21. Comorbidities causing complexity in treatment approach	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic

22. Amyloidosis	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
23. Genetic cardiomyopathies	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
24. End-organ dysfunction/ worsening renal or liver function related to HF	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
25. Edema despite escalating diuretics	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
26. Low blood pressure and high heart rate	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic
27. Referred patient was an inpatient at the institution where your clinic resides	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable (no inpt setting)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable (no inpt setting)	<input type="checkbox"/> Yes, should be an inclusion criterion <input type="checkbox"/> Yes, should be an exclusion criterion <input type="checkbox"/> No, this factor should not be considered when deciding who should access an HF clinic

I. Are there any other criteria for patients to receive care at your clinic that we have missed? Think about risk status, comorbid conditions and non-clinical characteristics.

- Yes
- No

b. If yes, please specify (and be sure to denote for each whether it is an inclusion or exclusion criterion for your clinic):

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J. Are there any other criteria you think should be considered for patients to receive care at any HF clinic that were not listed above? Think about risk status, comorbid conditions and non-clinical characteristics.

- Yes
- No

b. If yes, please specify (and be sure to denote for each whether it should be an inclusion or exclusion criterion):

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K. Are these patient criteria stated explicitly for referrers? (check all that apply)

- Yes, they are all on our referral form, website and /or clinic marketing materials we send to referral sources
- Yes, but not all of the factors are exhaustively listed somewhere accessible to referring providers
- No

L. Have you had to change your clinic inclusion / exclusion criteria in the past due to volume / capacity issues?

- No
- Yes

i. If yes, please describe the changes:

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M. Please let us know if you have any other thoughts on patient access to HF clinics:

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N. Lastly, we have been able to identify tertiary HF clinics fairly well. Do you know of any clinics outside of this setting, or potentially clinics in internal medicine that deal with HF and other patients? If yes, please provide their email address so we can have more generalizable results:

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Thank you for your time.

## APPENDIX E EMAIL INVITE FOR HF PATIENTS FOR PARTICIPATION IN STUDY – 1

**This is a research recruitment email inviting you to participate in our brief survey aimed at understanding patient access and physician referral to heart function clinics.**

Dear Heart Failure (HF) Patient,

Along with Canadian HF experts, we are conducting a study investigating referrals and access to heart function clinics across the country. This study is supported through a York University Graduate fellowship under the supervision of Prof. Sherry Grace.

If you are not interested, we respect your decision.

### **WHAT DO I HAVE TO DO?**

If you are willing to participate, please email [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca) and we will schedule an appointment for the interview at your convenience. The qualitative interview aimed at understanding factors affecting HF clinic access from patient perspectives in more depth. The interview will take place online (zoom), for approximately 30 minutes.

Also, we will send you a consent form to sign in closer to the date through email. Please send the form signed back to us before the scheduled interview. The consent form outlines that all information supplied will be held in confidence, and your name and your organization's name will not appear in any report or publication of the research.

### **BENEFITS TO PARTICIPATION**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

If have any questions or comments about the study, please let us know by emailing [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca). or if for any reason you prefer not to answer in the interview, you may skip that question. If you are not interested, we will then no longer contact you about this study.

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.

Thank you in advance for your time and consideration of this important study.

Sincerely,

Sherry Grace, PhD  
Professor, York University &  
Sr. Scientist, University Health Network

**APPENDIX F EMAIL INVITE FOR HF CLINIC REFERRER SURVEY PARTICIPATION**  
(STUDY – 2)

**This is a research recruitment email inviting you to participate in our brief survey aimed at understanding patient access and physician referral to heart function clinics.**

Dear Heart Failure (HF) Patient Care Provider,

Along with Canadian HF experts, we are conducting a study investigating referrals and access to heart function clinics across the country. This study is supported through a York University Graduate fellowship under the supervision of Prof. Sherry Grace.

If you do not treat heart failure patients, please accept our apologies for contacting you. Email [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca) and we will remove you from our list and not contact you again.

**WHAT DO I HAVE TO DO?**

If you are willing to participate, please click on this link:

<https://redcap.apps01.yorku.ca/surveys/?s=EY8FYFEHA8>. This will take you to a consent form in REDCap. This outlines that all information supplied will be held in confidence, and your name and your organization's name will not appear in any report or publication of the research.

If you are agreeable and click to consent, the survey will appear. The survey takes approximately 8 minutes to complete. You can go back and finish the survey at another time if desired.

**BENEFITS TO PARTICIPATION**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

We hope that you will fill out the questionnaire soon. If have any questions or comments about the study, or if for any reason you prefer not to answer the survey, please let us know by emailing [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca). If you are not interested, then we will then no longer contact you about this study.

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.

### **ONTARIO PROVIDERS: INTERVIEW?**

If you are from Ontario and would be willing to take part in a separate qualitative interview aimed at understanding factors affecting HF clinic referrals in more depth, please email [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca) as well. This could take place online (zoom), for approximately 30 minutes, at your convenience.

Thank you in advance for your time and consideration of this important study.

Sincerely,

Sherry Grace, PhD  
Professor, York University &  
Sr. Scientist, University Health Network

**APPENDIX G EMAIL INVITE FOR HF CLINIC PROVIDERS' SURVEY PARTICIPATION**  
(STUDY - 3)

**This is a research recruitment email inviting you to participate in our brief survey aimed at understanding patient access and physician referral to heart function clinics.**

Dear Heart Function Clinic Provider,

Along with Canadian HF experts, we are conducting a study investigating referrals and access to heart function clinics across the country. This study is supported through a York University Graduate fellowship under the supervision of Prof. Sherry Grace.

If you do not treat heart failure patients, please accept our apologies for contacting you. Email [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca) and we will remove you from our list and not contact you again.

**WHAT DO I HAVE TO DO?**

If you are willing to participate, please click on this link:

<https://redcap.apps01.yorku.ca/surveys/?s=EY8FYFEHA8>. This will take you to a consent form in REDCap. This outlines that all information supplied will be held in confidence, and your name and your organization's name will not appear in any report or publication of the research.

If you are agreeable and click to consent, the survey will appear. The survey takes approximately 8 minutes to complete. You can go back and finish the survey at another time if desired.

**BENEFITS TO PARTICIPATION**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

We hope that you will fill out the questionnaire soon. If have any questions or comments about the study, or if for any reason you prefer not to answer the survey, please let us know by emailing [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca). If you are not interested, then we will then no longer contact you about this study.

Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.

### **ONTARIO PROVIDERS: INTERVIEW?**

If you are from Ontario and would be willing to take part in a separate qualitative interview aimed at understanding factors affecting HF clinic referrals in more depth, please email [sherry.grace@uhn.ca](mailto:sherry.grace@uhn.ca) as well. This could take place online (zoom), for approximately 30 minutes, at your convenience.

Thank you in advance for your time and consideration of this important study.

Sincerely,

Sherry Grace, PhD  
Professor, York University &  
Sr. Scientist, University Health Network

## APPENDIX H. CONSENT FORMS

### I INTERVIEW CONSENT FORM FOR HEART FAILURE PATIENTS (STUDY - 1)



#### CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

**Study Title:** Multi-Method Study on Referral and Access to Heart Function Clinics

**Investigator/Study Doctor:** Sherry L Grace, PhD (Principal Investigator); Lusine Abrahamyan, PhD (co-investigator); Taslima Mamataz, PhD student (co-investigator)

**Contact Information:** Email: [Sherry.Grace@UHN.ca](mailto:Sherry.Grace@UHN.ca);

Phone number: (416) 603-5800 ext. 3495

#### **Introduction:**

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on the study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you

make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

**Background/Purpose:**

Heart function (HF) clinics have been shown to improve the health conditions of patients with HF like you. However, only a small portion of patients who could benefit from these clinics are able to access it. You are being invited to participate in this study to help us better understand the various factors that influence access to heart function clinics. In addition to interviewing patients like you, we will be interviewing policymakers, HF clinics, and doctors that refer HF patients to these clinics so we have a broad understanding of the issues affecting your access to these clinics.

**Study Design:** Qualitative research: Semi-structured interviews

**Study Procedure:** The interview session will take about 30 minutes, and will be held online using zoom video conferencing software if that is okay with you, or just on the phone if you prefer. We will be asking you about your experience being referred to an HF clinic (if you were), whether anything could have been done to make it easier for you to go to an HF clinic, and about whether you went or not.

**Risks:** We do not think there is anything in this study that could harm you, but some questions may seem sensitive or personal. If there are questions that you do not want to answer, you can say so or choose not to answer them and the interviewer will move on to the next question. If you decide you no longer want to participate in this study, you may stop at any time.

The use of zoom video conferencing software might come with privacy and security risks. To address this, participants shall be informed prior to the start of interviews not to provide names or personal identifiers on both video and audio recordings.

**Benefits:**

You may not direct benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

**Confidentiality:**

Your confidentiality will be respected. Information that discloses your identity will be maintained in confidence, within the provisions of the law in Canada. All information about you will have a code number on it instead of your name, and all documents will be identified only using this code number.

You should not to provide your name or any identifiers that could be used to identify yourself or others during the recording of the interview (but if you do, we will remove those). After transcription of interviews, we will destroy the video recordings (if you agreed to video recording) in line with UHN policies; only the audio files will be kept. The transcribed files, and the audio recordings from the interviews, will be stored in password-protected computer files on a secure server.

**Personal Health Information**

If you agree to join this study, we will collect the following information:

- Your age,
- sex,
- whether you live in an urban or rural area,
- your type of heart failure if you know it, how long you have had heart failure, and if you remember ever going to the emergency department for your heart failure or not

We will keep any personal health information about you in a secure and confidential location for 25 years as required.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time

**Withdrawal from the Study:** You are free to withdraw from this study at any time.

Data:

If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let the study investigator know.

**Costs and Reimbursement:** There are no costs to participating in this study as interviews will be conducted using a video conferencing software

**Rights as a Participant:**

By signing this form, you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:** There are no known conflicts of interest.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: *Sherry Grace: (416) 603-5800 ext. 3495*

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

\_\_\_\_\_

Print Study Participant's Name

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

\_\_\_\_\_

Print Name of Person  
Obtaining Consent

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

Please indicate interview format you prefer (check 1 box):

Video recording

interview via video, but record audio only

audio only

II INTERVIEW CONSENT FORM FOR HEALTH CARE PROVIDERS (HF CLINIC REFERRERS AND HF CLINIC PROVIDERS) AND POLICYMAKERS (STUDY - 1)



**CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY**

**Study Title:** Multi-Method Study on Referral and Access to Heart Function Clinics

**Investigator/Study Doctor:** Sherry L Grace, PhD (Principal Investigator); Lusine Abrahamyan, PhD (co- investigator); Taslima Mamataz, PhD student (co-investigator)

**Contact Information:** Email: [Sherry.Grace@UHN.ca](mailto:Sherry.Grace@UHN.ca);

Phone number: (416) 603-5800 ext. 3495

**Introduction:**

You are being asked as a heart function clinic referrer, provider and / or policymaker to take part in this research study. The form includes details on the study's risks and benefits that you should know before you decide if you would like to take part.

Participation in this study is voluntary.

**Background/Purpose:**

Heart function (HF) clinics have been shown to improve the outcomes of patients with HF. Despite the benefits, many patients do not access HF clinics. There are many reasons related to the health system, providers and patients themselves. There is little information on the factors here in Canada. You are being invited to participate in this study to help us better understand the policy and provider-level factors that influence access to heart function clinics. In addition to you, we are seeking to interview patients and HF clinics to have a broader understanding of the factors at play.

**Study Procedure:**

You are asked to take part in a qualitative interview held online using zoom, or on the phone if you do not wish to use a videocall. The interview session will take about 30 minutes. We will be asking you about your thoughts regarding the utilization of heart function (HF) clinics, including factors that influence the process of referrals

**Risks:**

The use of zoom video conferencing software might come with privacy and security risks. To address this, participants shall be informed prior to the start of interviews not to provide names or personal identifiers on both audio and video recordings.

**Benefits:**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

**Confidentiality:**

Your confidentiality will be respected. Information that discloses your identity will be maintained in confidence, within the provisions of the law in Canada. All information about you

will have a code number on it instead of your name, and all documents will be identified only using this code number. You should not provide your name or any identifiers that could be used to identify yourself or others during the recording of the interview (but if you do, we will remove those). After transcription of interviews, we will destroy the video recordings (if you agreed to video recording) in line with UHN policies; only the audio files will be kept. The transcribed files, and the audio recordings from the interviews, will be stored in password-protected computer files on a secure server. Study materials will be stored in a secure and confidential location for 25 years as required.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind and leave the study at any time by not completing the survey.

**Withdrawal from the Study:**

You are free to withdraw from this study at any time.

Data:

If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let the study investigator know.

**Costs and Reimbursement:**

There are no costs to participating in this study as interviews will be conducted using a video conferencing software.

**Rights as a Participant:**

By agreeing to take part in this study, you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:** There are no known conflicts of interest.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: *Sherry Grace: (416) 603-5800 ext. 3495*

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

Consent:

This study has been explained to me and any questions I had have been answered. I understand the nature of this project and wish to participate.

\_\_\_\_\_

Print Study Participant's Name

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

\_\_\_\_\_

Print Name of Person  
Obtaining Consent

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

Please indicate interview format you prefer (check 1 box):

Video recording

interview via video, but record audio only

audio only

### III INFORMED CONSENT FORM FOR HF REFERRERS (STUDY - 2)



#### CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

**Study Title:** Multi-Method Study on Referral and Access to Heart Function Clinics

**Investigator/Study Doctor:** Sherry L Grace, PhD (Principal Investigator); Lusine Abrahamyan, PhD (co- investigator); Taslima Mamataz, MPH, Doctoral student (co-investigator)

**Contact Information:** Email: [Sherry.Grace@UHN.ca](mailto:Sherry.Grace@UHN.ca);

Phone number: (416) 603-5800 ext. 3495

#### **Introduction:**

You are being asked as a healthcare provider who may refer patients to heart function clinics to take part in this research study. The form includes details on the study risks and benefits that you should know before you decide if you would like to take part.

Participation in this study is voluntary.

#### **Background/Purpose:**

Heart function (HF) clinics have been shown to improve the outcomes of patients with HF. Despite the benefits, many patients do not access HF clinics. There are many reasons related to the health system, providers and patients themselves. There is little information on the factors here in Canada. You are being invited to participate in this study to help us better understand the referring provider-related factors that influence access to HF clinics. The overall project involves not only the referring provider survey you are considering, but we are also doing a literature review, qualitative interviews and examining clinic inclusion / exclusion criteria.

**Study Procedure:**

You are asked to respond to an online survey that takes about 8 minutes to complete.

**Risks:**

We do not foresee any risks or discomfort from your participation in the research. You may refuse to answer any question(s) that you do not wish to answer.

**Benefits:**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

**Confidentiality:**

Your confidentiality will be respected. Surveys will be kept completely anonymous and no personal information will be requested. Email information will not be linkable to

survey responses. Your responses will be identifiable only by a research identification number. Study materials will be stored in a secure and confidential location for 25 years as required.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind and leave the study at any time by not completing the survey.

**Withdrawal from the Study:**

You are free to withdraw from this study at any time.

Data:

If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let the study investigator know.

**Costs and Reimbursement:**

You will not receive payment for your participation.

**Rights as a Participant:**

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:** There are no known conflicts of interest.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: *Sherry Grace: (416) 603-5800 ext. 3495*

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

Consent:

This study has been explained to me and any questions I had have been answered. I understand the nature of this project and wish to participate.

I am not waiving any of my legal rights by completing this form. My checkmark below indicates my consent.

I consent

Today's date (DD-MM-YY) \_\_\_\_\_

## IV INFORMED CONSENT FORM FOR HF CLINIC PROVIDERS (STUDY - 3)



### CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

**Study Title:** Multi-Method Study on Referral and Access to Heart Function Clinics

**Investigator/Study Doctor:** Sherry L Grace, PhD (Principal Investigator); Lusine Abrahamyan, PhD (co- investigator); Taslima Mamataz, MPH, Doctoral student (co-investigator)

**Contact Information:** Email: [Sherry.Grace@UHN.ca](mailto:Sherry.Grace@UHN.ca);

Phone number: (416) 603-5800 ext. 3495

#### **Introduction:**

You are being asked as a healthcare provider who may refer patients to heart function clinics to take part in this research study. The form includes details on the study risks and benefits that you should know before you decide if you would like to take part.

Participation in this study is voluntary.

#### **Background/Purpose:**

Heart function (HF) clinics have been shown to improve the outcomes of patients with HF. Despite the benefits, many patients do not access HF clinics. There are many reasons related to the health system, providers and patients themselves. There is little information on the factors here in Canada. You are being invited to participate in this study to help us better understand the referring provider-related factors that influence access to HF clinics. The overall project involves not only the referring provider survey you are considering, but we are also doing a literature review, qualitative interviews and examining clinic inclusion / exclusion criteria.

**Study Procedure:**

You are asked to respond to an online survey that takes about 8 minutes to complete.

**Risks:**

We do not foresee any risks or discomfort from your participation in the research. You may refuse to answer any question(s) that you do not wish to answer.

**Benefits:**

You may not directly benefit from being in this study. However, information learned from this study may help us improve the management of heart failure in the future.

**Confidentiality:**

Your confidentiality will be respected. Surveys will be kept completely anonymous and no personal information will be requested. Email information will not be linkable to

survey responses. Your responses will be identifiable only by a research identification number. Study materials will be stored in a secure and confidential location for 25 years as required.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind and leave the study at any time by not completing the survey.

**Withdrawal from the Study:**

You are free to withdraw from this study at any time.

Data:

If you decide to leave the study, you have the right to request withdrawal of information collected about you. Let the study investigator know.

**Costs and Reimbursement:**

You will not receive payment for your participation.

**Rights as a Participant:**

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

**Conflict of Interest:** There are no known conflicts of interest.

**Questions about the Study:**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: *Sherry Grace: (416) 603-5800 ext. 3495*

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

Consent:

This study has been explained to me and any questions I had have been answered. I understand the nature of this project and wish to participate.

I am not waiving any of my legal rights by completing this form. My checkmark below indicates my consent.

I consent

Today's date (DD-MM-YY) \_\_\_\_\_