

Referral and Access to Heart Function Clinics: A Realist Review

Running Title: Heart Function Clinic Access - Realist Review

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Abstract

Rationale, aim and objectives: Heart failure (HF) clinics are highly effective, yet not optimally utilized. A realist review was performed to identify contexts (e.g., health system characteristics, clinic capacity and siting) and underlying mechanisms (e.g., referring provider knowledge of clinics and referral criteria, barriers in disadvantaged patients) that influence utilization (provider referral [i.e., of all appropriate and no inappropriate patients] and access [i.e., patient attends ≥ 1 visit]) of HF clinics.

Methods: Following an initial scoping search and field observation in a HF clinic, we developed an initial program theory in conjunction with our expert panel, which included patient partners. Then, a literature search of seven databases were searched from inception to December 2019, including Medline; Grey literature was also searched. Studies of any design or editorials were included; studies regarding access to cardiac rehabilitation, or a single specialist for example, were excluded. Two independent reviewers screened the abstracts, and then full-texts. Relevant data from included articles was used to refine the program theory.

Results: 29 papers from 5 countries (3 regions) were included. There was limited information to support or refute many elements of our initial program theory (e.g., referring provider knowledge/beliefs, clinic inclusion/exclusion criteria), but refinements were made (e.g., specialized care provided in each clinic, lack of patient encouragement). Lack of capacity, geography and funding arrangements were identified as contextual factors, explaining a range of mechanistic processes, including patient clinical characteristics and social determinants of health as well as clinic characteristics, that help to explain inappropriate and low use of HF clinics (outcome).

Conclusion: Given the burden of HF and benefit of HF clinics, more research is needed to understand, and hence overcome sub-optimal use of HF clinics. In particular, an understanding from the perspective of referring providers is needed.

Keywords: Realist review; heart failure; health service; disease management; sex differences; nursing

INTRODUCTION

Heart failure (HF) is a major health problem, affecting about 26 million people worldwide¹. The risk-adjusted mortality after HF diagnosis is 10% at 30 days, and 25% at 1 year². HF has the second highest readmission rate of any health condition (21% within 30 days)³. The annual global estimated cost burden of HF is approximately \$108 billion United States (US) dollars⁴.

HF clinics are specialized, outpatient clinics offering assessment and monitoring, medication management and adjustment, as well as self-management education by a multidisciplinary team⁵. These 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%⁶⁻⁸. They are also shown to be cost-effective⁹. Accordingly, referral to these disease management clinics is recommended by all major HF clinical practice guidelines¹⁰⁻¹².

Despite the effectiveness of these clinics, rough estimates are that only about 10% of hospitalized HF patients access HF clinics¹³; while not all patients require such specialized care¹⁴, it is generally agreed that this is sub-optimal. Moreover, biases in referrals and access to these clinics have been identified, such that it is not the patients who need it most that do¹⁵. The reasons for this are not well understood^{16,17}.

The purpose of this study was to conduct a realist review to identify mechanisms and underlying processes that influence (in)appropriate utilization (provider referral and patient access) to HF clinics. In accordance with consensus-derived data definitions for other outpatient cardiology clinics²⁰, we defined referral as the receipt of a completed referral form or electronic referral by a HF clinic (with the outcome desired being referral of all indicated patients [i.e.,

“appropriate], and no referral of patients who are not indicated [i.e., “inappropriate]), while access was defined as attendance at at least one HF clinic visit by a patient (with the outcome desired being that all referred patients would attend).

METHODS

Study Design

Realist reviews unpack the relationships between context, mechanisms, and outcomes (C-M-O framework), addressing “...*what works, how, in what circumstances and to what extent*”¹⁸. Realist review is particularly appropriate to address the objectives of this study, as HF clinics are complex interventions, delivered within varying health system contexts, resulting in a range of possible mechanistic theories, that then result in the (in)appropriate utilization of HF clinics.

This realist review is prepared in accordance with the Realist and Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES I) reporting guidelines¹⁹. The review was registered on PROSPERO (CRD42020167943). Online Supplemental Table 1 highlights the key steps undertaken.

Expert Panel, Developing Initial Program Theory & Clarifying Scope

This realist review commenced with the convening of an expert panel comprising research, clinical (acute HF care and clinic providers) and policy experts in the field of HF care as well as patient partners. Through their collective experience and the preliminary search described below, the expert panel provided input on the review question and the initial program theory (Figure 1), namely possible underlying theories on the various contextual factors surrounding HF care delivery that activate mechanistic processes which may explain the

(in)appropriate use (i.e., referral and access) of HF clinics (i.e., C-M-O configurations). To complement this and inform the initial program theory, the first author performed fieldwork in a large, urban academic HF clinic, undertaking structured observation. The expert committee was consulted multiple times to ensure that this process was ongoing and iterative.

Search Methods

We also conducted an initial exploratory literature search to inform the creation of the program theory (Figure 1), including consideration of policies, guidelines, and some HF clinic websites¹⁵. Following this, a second purposeful literature search was conducted to ensure that explanatory theories to inform the study objective were sought²¹. Seven databases were searched from inception to December 2019: Medline, Embase, Emcare, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, PsycINFO and PubMed (non-Medline). We placed no time restrictions on the article search due to the limited research identified in this field through our initial search. The search strategies were developed in collaboration with an Information Specialist [MP] utilizing the PICO framework, subject headings as appropriate for each database, and free-text terms relevant to the topical concepts. See Online Supplemental Table 2 for the detailed Medline search strategy. Selected websites were also searched to identify grey literature during and after analysis of peer-reviewed literature²², including CorHealth Ontario, Health Quality Ontario, the Center for Reviews and Dissemination, major cardiac societies (e.g., American Heart Association) and Google.

Inclusion / Exclusion Criteria

Citations were included if they were relevant to the initial program theory and outcome of interest (i.e., whether the study “addressed the theory under test”). Studies/reports published as full manuscripts were included, including editorials. Studies published only in English and French were included. Studies that examined cardiac rehabilitation access that included non-HF patients were excluded, as were those that were regarding access to a specialist (not multidisciplinary clinic), or regarding referral to advanced care centers for consideration of device implantation or transplant unless it was clear it was an HF clinic.

Screening Methods

The search results were uploaded to Mendeley for duplicate removal. Following this, the unique citations were transferred to Covidence (covidence.org). As a means to ensure consistency in the screening process, the review team then met for a calibration meeting, to consider citations serially for relevance and apply the inclusion/exclusion criteria; this process was repeated until all 3 raters were making consistent and consensual inclusion decisions on citations. We were very liberal at the title/abstract screening stage, to consider full-texts of citations where any content could relate to the program theory. Citation screening was then independently conducted by two investigators, first of title/abstract, then of potential full-texts. Disagreements were resolved by the senior author.

Realist Quality Appraisal and Data Abstraction

Article quality assessment is approached differently in realist methods than systematic reviews, but article bias is similarly considered. Included reports were assessed based on relevance and rigour (i.e., “whether a particular inference drawn by the original researcher has sufficient weight to make a methodologically-credible contribution to the test of a particular

intervention theory”)²¹ (Supplement 1). To do this, each study was examined in detail to ensure that these criteria were met. We developed an extraction tool to consider these parameters and also collect information on: study design and any sources of bias; study characteristics (e.g., type of participants recruited, age range where applicable, study objectives etc.); country where the study was conducted; and information relevant to our program theory.

The data extraction process was iterative, occurring over several rounds, to ensure that information on context and mechanisms were thoroughly identified. This was done independently by the first author, and then reviewed by the second author to ensure that all relevant information was duly obtained; the senior author checked several times and was satisfied.

Synthesis

Synthesis of the extracted information was informed by the initial program theory. We utilized narrative synthesis to aggregate relevant information through a retroductive strategy, considering where there was evidence-based support to the various elements of our C-M-O configurations, and where refinement was needed. In cases where no evidentiary basis to elements of our program theory was identified, additional searching was undertaken from somewhat broader literature (e.g., referral and access to cardiac rehabilitation). The findings were grouped by geographical region as a means to explore potential contextual differences in the C-M-O framework.

RESULTS

Following the search process, 29 studies were included in this review (Figure 2), of which three articles were retrieved via grey literature searching²³⁻²⁵. The included studies were

from five different countries, namely 11 from Canada, eight from the US, five from Sweden, three from Australia and two from the United Kingdom (Table 1). The nature of designs varied between cohort studies (i.e. retrospective or prospective) (n=10), chart reviews (n=5), cross sectional (n=3), review papers (n=3), editorials (n=2), mixed-methods (n=2), qualitative (n=1), case-control (n=1), descriptive and environmental scan (n=1).

Based on the reviewed studies, we found no evidence related to many C-M-O elements outlined in the initial program theory (Figure 1). Given the frontline experience of the experts who helped draft the initial program theory, we believe the lack of evidence does not negate these elements, but rather underscores the need for more research in this field. We describe 3 C-M-O configurations in the figure.

However, we did find ample evidence supporting two mechanisms in the identified studies (Figure 1), namely the influence of social determinants (i.e., age, sex, ethnicity, socioeconomic status) in access to HF clinics, and variation in terms of the clinical manifestations. These mechanisms explain inequities in referrals and access to HF clinics. The revised program theory is shown in Figure 1.

Contexts

Lack of Clinics/Capacity

The overarching insights garnered from studies addressing this reflected a lack of capacity to accept all appropriate HF patients²⁶. This was supported by evidence from an evaluation of clinics in a Canadian province that found a few health regions had no HF clinics²⁷, and findings from Australia and the US which show that HF clinics are located predominantly in

urban and metropolitan areas^{28,29}. Further, the situation in Canada where only 15% of HF patients were referred, underscore challenges with capacity¹⁶.

Geographic barriers in patient access to HF clinics

Wijeysundera *et al.* in their environmental scan of HF clinics in Ontario, Canada found significant geographic variations, with most clinics located in the South and Central regions of the province; A few regions were found not to have any clinics²⁷. In Australia, most of the clinics were located in metropolitan areas, with only 21% of clinics located in rural areas²⁸. In rural South Carolinian HF patients who were referred to clinics but failed to attend, reported barriers included access (distance to clinic location) and lack of a personal vehicle²⁹.

Funding arrangements

Financial arrangements in terms of healthcare coverage and service reimbursement to clinicians or clinics were also important to context. It should be noted that while most of the countries explored in this review, with the exception of the US, have universal healthcare coverage, variation exists with respect to how outpatient HF disease management is funded. Here, we can provide a nice example of how context leads to the mechanisms we describe in detail below (see also configuration arrows in Figure 1). For example, despite universal healthcare coverage, half of the HF clinics in Australia were reported to be lacking in consistent funding²⁸. Similarly, in US HF clinics, the context of patients paying out-of-pocket costs explains social disparities observed in access to HF clinics^{17,30}. Additionally, it also appears that the type of clinic personnel impacts on funding, with nurse-led clinics more likely to be inadequately funded compared to physician-led clinics²⁸. This is also true for nurse-led clinics in

parts of Canada, where nurses or nurse-practitioners are unable to bill the government for services rendered to patients³¹.

Mechanisms

Clinical Characteristics

The vast majority of studies included in the review focused on differences in clinical manifestations or HF severity in patients referred or accessing HF clinics. In an evaluation of clinics in Ontario, Canada, patients had fewer comorbidities like diabetes (37% vs 46%) and hypertension (62% vs 85%) compared with the average Ontarian HF patient²⁶. Another Ontario study reported that having lower ejection fraction, and lower functional status were associated with HF clinic use¹⁶. Similarly, an evaluation of Canada-wide clinics also found that referred patients had fewer comorbidities^{23,32}. In Quebec clinics, factors associated with referral to an HF clinic at an earlier point in the disease trajectory included lower New York Heart Association (NYHA) functional class, and having no diabetes or chronic renal insufficiency³³. Another Quebec study found lower quality of life, having fewer comorbidities, and reduced ejection fraction (vs preserved) were associated with increased referral likelihood³⁴. Nova Scotia HF patients accessing clinics had higher plasma hemoglobin, higher rates of previous myocardial infarction, lower ejection fraction (EF), serum creatinine and blood pressure than those not seen in HF clinics³⁵.

In the US, patterns observed from Akosah et al. show that patients referred to HF clinics had severe left ventricular dysfunction, lower left ventricular ejection fraction and more comorbidities like dysrhythmias, renal disease, and hypotension³⁶. In a larger evaluation study of 235 US clinics, mixed patterns were observed, as patients with fewer comorbidities such as

diabetes, atrial fibrillation, anemia, respiratory disease, ischemic heart disease, cerebrovascular disease, and depression were more likely to be referred, yet characteristics such as renal insufficiency and smoking were more prevalent in referred patients¹⁷. Findings from New York, US showed that most HF clinic patients presented with worse symptoms and functional impairment, a high degree of frailty, and had an increased risk of re-hospitalization (from any cause within 30 days)³⁷.

In Swedish HF patients who were referred to a clinic, concomitant cardiovascular disease, increased QRS width on electrocardiogram, and elevated serum creatinine and N-terminal pro b-type natriuretic peptide (NTproBNP) levels were more prevalent³⁸. Additionally, those referred had lower EF, while 62% of patients had a NYHA class II³⁸. These findings were questioned in a large analysis of Swedish clinics using registry data which found that patients seen in a HF clinic were likely to have had HF for a shorter duration, HF with reduced ejection fraction, lower blood pressure and NT-proBNP levels, and higher body mass index, estimated glomerular filtration rate, and hemoglobin levels. Moreover, they were less likely to suffer from comorbidities and more likely to receive evidence-based HF therapy³⁹. Finally, in Australia, the clinical characteristics of clinic patients at initial visit showed that they had a mean ejection fraction of 32%, multiple comorbidities and ischemic HF⁴⁰.

The patterns observed reflect that patients who utilize these clinics appear to be either sicker than those who did not, suggesting referral appropriateness, or the opposite that healthier patients are accessing them, suggesting bias/inappropriate use. Regional variation was also observed. In addition, the broad range of clinical indicators outlined in the studies as determinants of HF clinic referral and access underscores the need for clear and consistent consensus criteria for referral and access to improve current practice.

Indeed, while most of the studies assessed did not provide explicit information on referral criteria used in determining which patients to treat in clinics, the evidence from these studies suggest that clinics are allowed considerable latitude in defining their referral criteria. The lack of a consensus on criteria (see guideline recommendations summarized elsewhere)¹⁵ could explain the inconsistencies observed in the clinical characteristics of patients referred to, or accessing, HF clinics. A recent American guideline has laid out specific criteria delineated by the acronym I-NEED-HELP¹⁴ which may facilitate standardization. Yet, the issue of referrals cannot be tackled in isolation. Contextual factors such as the lack of funding and capacity problems play a significant part in influencing how narrowly clinics set their referral criteria. One way to addressing this might be utilizing the strategy set out by Ontario, Canada, which is to treat HF through an integrated and collaborative strategy called the spoke-hub-node model^{5,41}. This strategy aims to efficiently distribute HF care across all tiers of healthcare service delivery, by applying a risk model which assigns patients to different tiers based on their status.

Patient healthcare use

In Canada, visits to the emergency room in the preceding 6 months, not having regular follow-up by a physician in the past for HF³³, and not using an HF medication at the time of an emergency visit were associated with higher likelihood of referral³⁴. In the US, patients with implantable cardiac defibrillators³⁶ and other implantable devices¹⁷ were more likely to be referred. An opposing trend was observed in Sweden, where patients who used more medications were most likely referred.

The patterns of healthcare use described are indicative of patients who are most in need of specialized HF services as provided by clinics, and indeed emergency room visits are listed in

several international guidelines as an indication for HF clinic referral¹⁵. The conflicting patterns in terms of medication use in Canada and Sweden can both point to need. Lack of access to medications might be indicative of a lack of access to healthcare, while more medications might indicate increased severity and/or complexity; patients in both instances would be well served in HF clinics.

Sex and gender differences

The most-commonly reported disparity identified in these papers was sex differences in access to HF clinics. One chart review of patients attending 9 HF clinics in Ontario, Canada between 1995-2010 found women to be significantly under-represented in HF clinics. The average percentage of women accessing these clinics was 35.5%, ranging from 26% to 41% across the clinics⁴², which seems disproportionate given the high prevalence of HF in women⁴²⁻⁴⁴. This pattern was also observed in other parts of Canada as well^{32-35,44}. In the US, similarly Akosah et al. found that 71% of men were referred to HF clinics³⁶. In an assessment of 338 country-wide “Get-with-the-guideline” program hospitals, it was observed that men were over-represented in HF programs compared to women³⁰.

In the UK, one study found that despite women having greater HF severity, evidenced by left ventricular systolic dysfunction, more men (61%) were referred to HF clinics than women⁴⁵. Likewise two Swedish studies both reported sex disparities, with men representing a higher proportion of patients being seen in these clinics^{38,39}.

Some potential mechanisms to explain the reported disparities were postulated in these studies. Again, the clinic access differences observed are not readily explained by epidemiological differences in the prevalence or severity of HF, given both are greater in

women⁴²⁻⁴⁴. Further, in some of the studies reported, women were also found to have worse functional status at the point of referral than men^{42,44}, demonstrating greater need.

Sex or gender-based referral biases might be tied to differences in clinical presentation of HF, as women are more likely to have HF with preserved systolic function^{44,46}. Hence, women might be being referred later in their HF trajectory, or not deemed appropriate for specialized HF care³⁴. Indeed, some HF clinics may have historically been less likely to accept patients with preserved ejection fraction⁴⁴. However, even after adjusting for systolic dysfunction and other patient characteristics, these sex differences still persist³⁴. In addition, because women sometimes present differently, their symptoms have often being conflated with that of other diseases, resulting in poorer diagnosis and leading ultimately to this poorer access to these clinics^{44,47}. Finally, the lack of supports for women with HF has also been suggested as an explanatory factor, given women with HF are more likely to live alone and to report logistical difficulties accessing HF clinics³⁴.

Age

Where tested, age differences in patients accessing HF clinics were reported. Across nine HF clinics in Ontario, Canada, significant variations in the age of participants were observed²⁶; The mean age of participants for each clinic ranged from 53.5 years to 75.1 years²⁶. In most studies, the overwhelming trend observed was that younger individuals with HF were more often represented in the HF clinics. In Canada, it was observed that older and more frail patients who perhaps might be better served in those clinics⁴⁸ utilized them less; this difference was particularly pronounced in older patients living in rural areas^{23,32}. Similar findings were reported

in Quebec^{34,44} and Nova Scotia³⁵, where it was found that patients who utilized HF clinics were relatively younger.

In the US, Akosah et al. found that compared to those who saw primary care doctors, participants referred to specialized HF clinics were younger (68 years compared with 76 years)³⁶. In the UK, participants with HF referred were found to be about 5 years younger as well⁴⁹. Findings from Sweden were also consistent³⁹.

The reported age-related differences in referral and access can be explained by a few theorized mechanisms. Older HF patients often present with more comorbidities⁵⁰ which might result in more medical appointments, and hence these patients may miss some or choose not to attend⁴⁴. Older patients may become frail, which can render them ineligible for some therapies such as ICDs, so these patients may not be referred to HF clinics, and thus not access other clinic offerings. Ageism in the field of cardiac care has also been reported⁵¹. It is not exactly clear if this is reflective of unconscious bias against older people, or if this is a result of intricate connections between age, social conditions and clinical manifestations such as cognitive problems in older individuals⁴⁴, as well as lack of support systems⁵². As with sex differences, the greater HF severity in older HF patients, and existence of more comorbidities and hence complexity for management point to greater, not lesser, need to access HF clinics.

Ethnic disparities

In the US, three studies reported ethnic differences in access to HF clinics. Deswal et al. found that in a Veteran population with good access to health care, African-Americans were found to access HF clinics relatively less when compared with white-Americans⁵³. Likewise, Koser et al. found that in an outpatient HF clinic in New York, over 84% of patients referred

were white, while only 13% Black patients were referred³⁷. Conversely, in an assessment of HF patients from over 235 “Get-with-the-guidelines” program hospitals, African-Americans were more likely to be referred compared with all other ethnic groups¹⁷.

It is not clear how much of the observed differences are reflective of legitimate ethnicity-related referral biases versus appropriate patterns given ethno-racial composition in clinic catchments. Deswal et al. attributed their observed disparities in access to lesser social support and racial dynamics in patient-doctor interactions⁵³. On the other hand, Koser et al. reported that their clinics were located in areas with a relatively homogenous white population, perhaps explaining their observed differences³⁷. However, the fact that the opposite association was observed with the intervention “Get with the guidelines” suggests that bias is occurring, but that systematic approaches can overcome it.

In Sweden, immigrant patients with HF were referred more often to nurse than physician-led HF clinics than Swedish-born individuals. The investigators attributed this to potential language barriers in the immigrant population, which render a nurse-led clinics where there is more time to spend with each patient as more suited to addressing the individualized needs of these patients⁵⁴. This finding raises questions about how physician knowledge of clinic characteristics (e.g., costs, location, provider expertise) impacts their referral practices, as was raised in our initial program theory.

Socioeconomic factors

Indicators of socioeconomic status were also found to be related with HF clinic access. In Ontario, patients who completed high school or greater were more likely to use HF clinics

compared with those who did not ¹⁶. Higher level of education was also found to be associated with referral to Quebec HF clinics in patients who visited the emergency department ³⁴.

In a Quebec multidisciplinary clinic, participants with income lower than \$20,000 (CAD) per year were found to be admitted to HF clinics much later than those with higher incomes ³³. Similarly, in Nova Scotia patients seen in HF clinics were significantly less likely to be living below the poverty line compared with those who received usual care³⁵.

Given the Canadian healthcare landscape where costs are fully covered by the government, these socioeconomic disparities are suggestive of inequities in referrals and access. These patterns are similar to patterns for other healthcare usage across Canada, where patients of lower socioeconomic status tend to utilize family physician services more, but specialized services less than those of higher socioeconomic status ^{55,56}. There are several potential mechanisms that might explain these disparities. It is possible that individuals with lower income, even with access to free healthcare, might struggle to afford the associated transportation costs ³³. Moreover, lower-income individuals rely heavily on employment income ⁵⁷, and as such might have to prioritize work over attending an HF clinic, given they generally are not offered outside of business hours ⁵⁸. Moreover, individuals with lower education, and hence potentially health literacy, might not understand the importance of HF clinics. Indeed, previous studies have shown that predictors of referral to specialized services include patient preferences and the ability to express the need for care ⁵⁹. Given that access to HF clinics requires a referral, these patients may be unable to self-advocate to referring physicians their need for specialized care. More studies outside of Canada will be needed to help contrast Canadian patterns with patterns in Europe, which has a similar health system, and the US, which does not and has some of the widest socioeconomic gaps of any developed country.

Other social and patient-related factors

Feldman et al. (Canada) found that living with someone was associated with a greater likelihood of being referred to an HF clinic ³⁴. A Swedish study also found that being married or cohabitating with a partner was found to be related with higher likelihood of referrals to HF clinics³⁹. It is unclear how this would impact referral. Perhaps these important others (who would likely not also be suffering from a chronic condition such as HF, and hence may also have better cognitive function) act as advocates to ensure optimal care, or perhaps they transport patients to clinic appointments ^{58,60}

Finally, a few more tangible factors were identified that impacted patient use of clinics. One US study reported that fear of death, as well as recommendations by healthcare providers and family members were the most important influences on attendance at an HF clinic ⁶¹. In an Australia study, patients listed a range of logistical deterrents to HF clinic attendance, including transportation issues, a lack of parking at the site, multiple medical appointments with conflicting appointment times, as well as scheduling of appointments during work hours ⁵⁸. These factors might act as barriers to clinic access by raising the incidental expenses and opportunity costs associated with healthcare use ⁶², thereby serving as disincentives to clinic access.

HF clinic characteristics

Lastly, having an established HF clinic at the hospital where patients are receiving acute care, as well as referral to other disease management programs were associated with HF clinic use ¹⁶. This is possibly because referring physicians at hospitals with HF clinics have an increased awareness of the benefits of disease management programs, making them more likely to refer.

DISCUSSION

This realist review aimed to identify mechanisms that influence appropriate referrals and access to HF clinics, according to context. Limited to no information was available to support or refute many elements of the initial program theory, however refinements were made with the available evidence pending further research. Overall, it appears that policy, clinic capacity and patient environment (e.g., geography) are the major contextual considerations related to HF clinic referral and access. The main mechanisms impacting appropriate referral and access demonstrated in the literature are biases related to social determinants of health, clinical characteristics of patients (including their healthcare use), and clinic policy (e.g., referral criteria).

Limitations

This review was limited to considering HF clinics as the main means to supporting specialized, outpatient care; this must be considered in the context of the continuum of HF care and the health systems in which they are embedded. Finally, as shown in the PRISMA flow diagram, there were 9 abstracts that were potentially-eligible, but the full-texts were not available in English or French for full consideration. Therefore, there may be some further information on this topic available which could not be analyzed herein. Moreover, an epub on HF clinic processes in Canada was released just before article submission (and hence after the search date) which may also contain further information⁶³.

Directions for Future Research

Primary studies, including qualitative studies that seek to understand the viewpoints of the range of stakeholders that play a vital role in the delivery and receipt of this intervention are

needed (e.g., policy-maker viewpoints, patients, clinics, primary care providers), to provide information on the contextual and mechanistic processes that contribute to the suboptimal and biased use of HF clinics. In particular, information from a range of physicians treating HF patients is needed to understand on what basis they refer patients, their knowledge and awareness of HF clinics in their region (including how to refer their patients), and their experiences with and attitudes regarding HF clinics.

Current guideline recommendations from North America and Europe suggest “high-risk” patients should be referred to HF clinics, but this is often defined in many different ways¹⁵, leading to confusion for referrers. Consensus on explicit referral criteria will be necessary to mitigate the disparities identified in this study. Given the limited capacity of HF clinic to treat all HF patients, somewhat narrow consensus guidelines on referral criteria may be needed, using the best available evidence on who benefits most.

Implications for Practice

The quality improvement program “Get-with-the-Guidelines” (<https://www.heart.org/en/professional/quality-improvement/get-with-the-guidelines/get-with-the-guidelines-heart-failure>) demonstrated promise in addressing ethnic, but not sex/gender, age or clinical biases in referrals by standardizing care^{64 17,30}. This perhaps suggests that we can and should standardize referral to mitigate bias, but we still need to make HF clinics equitably accessible to all patients (e.g., perhaps women and older patients have more transportation barriers). Further work, particularly addressing the problems with context (capacity, geographical access and funding) and social determinants of health, could support appropriate access to HF clinics for all patients.

To fully address system, geographic and social disparities in access to HF clinics, a deep understanding of the various policy-based and implementation bottlenecks to access to HF clinics in various regions will be required. This was particularly challenging given that each of the countries explored varied significantly in terms of how their health systems are structured. It appears however that a common theme is that access to HF clinics is limited across the board, signifying a capacity challenge. One way to address this might be expanding access using virtual-based technologies such as telemedicine ²⁵. We must remain true to the specialized, multidisciplinary outpatient approach, but creative models of virtual implementation that are cost-effective and accessible are needed ²⁵. This would ensure that individuals in rural areas for example, where capacity is significantly limited, are provided with opportunities to access HF clinics too.

Conclusion

Important contextual factors limiting HF clinic use are policy, capacity, funding and geography; mechanisms that lead to suboptimal use of HF clinics include lack of referral, social determinants of health (e.g., sex, socioeconomic status), clinical characteristics, referring provider knowledge and attitudes as well as factors related to the clinics themselves such as inclusion criteria and type of professions. However, the limited amount of identified information led to only a refinement of our initial program theory; more primary studies will be required to fully understand the various contexts, processes and mechanisms that explain why access and referral to HF clinics remains sub-optimal. Over and above support to augment clinic capacity, consensus on explicit referral criteria is needed, and then standardized implementation of those criteria may be promoted through adoption of proven quality improvement programs such as “Get with the Guidelines”.

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Table 1: Summary of Findings

Citation (<i>Region</i>)	Design	Sample & Setting	Access & Referral Measures	Relevant Findings
<i>Americas</i>				
Abrahamyan et al., 2013 ²⁶	Retrospective cohort study	N=902 from 9 Ontario, Canada HF clinics	Baseline differences in access to 9 Ontario HF clinics	Most patients were male, moderately symptomatic with an NYHA class of II or III and had a reduced LVEF (<40%). Compared with typical Ontario HF patients, the cohort was younger with a lower prevalence of comorbidities.
Abrahamyan et al., 2018 ⁴²	Retrospective cohort study	same Ontario, Canada HF clinics as above	Comparison of social and clinical profile of men and women attending Ontario HF clinics	More men treated in HF clinics overall. Women were older, had a higher prevalence of non-ischemic HF etiology, better systolic function, and worse functional class. They were also more likely to have difficulty accessing the clinic.
Aksoah et al., 2002 ³⁶	Retrospective cohort study	N=101 patients from the United States referred to an HF clinic or primary care physician after hospital discharge with HF	Demographic and clinical comparisons of patients referred to HF clinics compared with usual care	Referred patients were mostly male, younger, had more severe left ventricular dysfunction, worse LVEF, with a higher likelihood of renal disease, dysrhythmias, and hypotension.

Crowder, 2006 ⁶¹	Descriptive qualitative study	N=15 Patients referred and enrolled to an outpatient HF clinic in Arkansas	Referral patterns and influences on attendance at HF clinics	Majority of participants referred due to repeated hospitalizations. Fear of death recommendation by health care provider and family members were the biggest influences on enrolment at HF clinics.
Deswal et al., 2004 ⁵³	Retrospective cohort study	N=21,994 in a bi-ethnic US veteran population hospitalized with HF	Ethnic differences in access to HF care	Black patients r had a lesser number of clinic visits than White patients.
Ducharme, 2017 ³²	Editorial paper	N/A	Summary of findings from a systematic review examining Canadian HF clinics	Only 15% of patients were referred to an HF management program following hospitalizations. Patients were referred less if female, older and frail, had more comorbidities, and living in rural areas.
Feldman et al., 2009 ³³	Cross-sectional study	N=531 patients admitted to multidisciplinary HF clinics in Quebec	Factors associated with HF clinic utilization	Factors related to earlier admission at an HF clinic included being referred by a specialist, lack of prior follow-up for HF, lower NYHA functional class, younger age, higher educational level, higher

				income, and having two or more comorbidities.
Feldman et al., 2013 ³⁴	Prospective cohort study	N=549 patients recruited from 8 Quebec, Canada emergency departments	Gender and other disparities in referral to specialized multidisciplinary clinics	Factors associated with referral to an HF clinic included gender, younger age, higher level of education, living with someone, being less often on an HF medication and having HF with systolic dysfunction.
Gandhi et al., 2017 ²³	Systematic review	N=3,999 HF patients from 16 randomized controlled trials conducted in North America, Europe and the Western-Pacific.	Comparison of patients seen in multidisciplinary HF clinics versus control.	Patients referred less to the HF clinic were female, older, and had multiple comorbidities.
Gharacholou et al., 2011 ¹⁷	Observational, prospective study	N=57,969 patients hospitalized with HF from 235 Get-with-the-Guidelines hospitals in the United States.	Characteristics of patients referred to an outpatient disease program	19% of the cohort was referred to an HF disease management program. Referred patients were younger, more likely to be African-American, had lower rates of comorbidities, and higher rates of hospitalizations (≥ 1). Larger hospitals, such as those with cardiac surgery capability and academic affiliations, had higher referral rates.

Golwala et al., 2015 ³⁰	Observational, prospective study	N=105,619 patients from 338 Get-with-the-Guidelines hospitals in the United States.	Comparison of patient and hospital characteristics of patients with and without a cardiac rehabilitation referral.	Patient referred were younger, predominantly men, had lower comorbidities, and had more prior procedures (i.e. CABG, PCI). Southern centres had more referrals than Midwestern centres.
Gravelly et al., 2012 ¹⁶	Prospective cohort study	N=271 patients from 11 Ontario, Canada hospitals	Factors influencing referrals and use of HF clinics	Having an HF clinic at the hospital, referral to other disease management programs, higher education, lower stress, and lower functional status were found to be associated with greater clinic use.
Houde et al., 2007 ⁴⁴	Cross-sectional study	N=765 patients admitted to three Quebec, Canada HF clinics	Sex differences in baseline and clinical characteristics of patients utilizing HF clinics.	Mean LVEF was higher in women and they presented less often with systolic dysfunction. Referred patients were younger and more often male.
Howlett et al., 2009 ³⁵	Case-control study	N=8731 patients diagnosed with HF in Nova Scotia, Canada between 1997 and 2000	Comparison of characteristics of patients who utilized HF clinics vs those who did not.	Patients who utilized HF clinics were younger, more likely to be men, had lower ejection fraction, lower serum creatinine, lower BP, had higher body mass, plasma hemoglobin, and higher rates of previous

				myocardial infarction.
Koser et al., 2018 ³⁷	Retrospective analysis	N=415 patients from an outpatient HF clinic in New York, United States	Demographic and clinical characteristics of patients in the HF clinic.	Participants were primarily White. Most participants had a reduced ejection fraction ($\leq 40\%$), multiple medication changes, diuretic adjustments, and received up to 25 calls within 2 months of discharge suggesting that participants were sicker, older, more frail, and had a high likelihood of hospitalization.
Murray, 2017 ²⁹	Retrospective chart audit	N=50 no-shows to an HF clinic in South Carolina, US	Barriers to accessing an HF clinic	The two reported barriers to utilizing an HF clinic were access (distance to travel to the HF center from home) and lack of a personal vehicle. 33% of the sample lived within 11 miles of the HF center, and 67% lived in outlying rural communities of South and North Carolina.
Orr et al., 2015 ⁶⁵	Narrative review	N/A	HF management in skilled nursing facilities.	Factors such as lack of facility preparedness, lack of systematic disease management protocols, and traditional nursing home culture have

				led to relatively poorer quality in skilled nursing facilities when compared with hospitals.
Toronto Health Economics and Technology Assessment, 2011 ²⁴	Multi-methods paper	N=1,288 patients from 34 Ontario clinics	Characteristics of patients attending HF clinic	Age differences and differences in clinical presentation were observed across the clinics.
Wijeysundera et al., 2012 ²⁷	Environmental scan	N=143 HF clinicians from 34 clinics operating in Ontario, Canada	Disparities in access to HF clinics	There was substantial variation in access to HF clinics with two local health integrated networks having no identified clinic.
<i>Europe</i>				
Buttery et al., 2014 ⁴⁹	Cross-sectional study	N=106 patients aged 65 or older with HF in the United Kingdom	HF patients suitable for cardiac rehabilitation	Participants preferring to participate were 5 years younger than those preferring not to participate. Although about 75% percent of patients preferred to attend, only 20% were referred.
Hedemalm et al., 2008 ⁵⁴	Retrospective study	N=214 matched database of immigrants and Swedish patients with HF	Referral to a nurse-led HF clinic	More immigrants patients with HF were referred to a nurse-led HF clinic than Swedish patients.
Houghton & Cowley, 1997 ⁴⁵	Cross-sectional/Clinic audit	N=85 patients referred to a HF clinic in Nottingham	Comparison of clinical characteristics of patients.	Women were less likely to have left ventricular systolic dysfunction than men.

Jaarsma & Strömberg, 2014 ²⁵	Editorial	N/A	Evaluation of HF clinics and recommendations to improve access.	Disparities in access to HF clinic exist. The current model of hospital-based clinics or specialty-only resulted in limited access to older and frail patients.
Mejhert & Kahan, 2015 ³⁸	Prospective cohort study	N=102 newly diagnosed HF patients referred to an outpatient management program in Stockholm, Sweden	Comparisons of patients with a confirmed HF diagnosis vs those without.	Male gender, concomitant cardiovascular disease and medications, increased QRS width on ECG, and elevated serum creatinine and NTproBNP levels were more common in the 46 HF patients, whereas diseases of the respiratory tract were more common in the 52 non-HF patients. Left ventricular ejection fraction in the HF group was considered normal in 6 patients, and the reduction was mild, moderate, and marked in 26, 6, and 6 patients, respectively. NYHA class I, II, III, and IV was present in 2, 38, 6, and 0 patients, respectively.
Savarese et al., 2019 ³⁹	Prospective Cohort study	N=40,992 outpatients from the Swedish HF registry	Predictors of referrals to nurse-led HF clinics.	HF with reduced ejection fraction, HF with mid-range EF subtypes,

				<p>shorter HF duration, higher NT-proBNP levels, and absence of comorbidities, such as anemia, atrial fibrillation, valvular disease, peripheral artery disease, history of stroke, lung disease, lower blood pressure, and current or previous smoking, were confirmed as independent predictors of planned follow-up in a nurse-led HF clinic after adjustments. Patients with planned follow-up were more likely to be male, younger, have higher educational status and income, be registered as outpatients in the SwedeHF registry, be married or cohabitating, or have specialist follow-up care.</p>
Thorvaldsen & Lund, 2019 ⁶⁶	Review paper	N/A	Clinical criteria for referrals to HF clinics.	<p>“No validated criteria or cut-off values for referral to an advanced HF clinic or HF specialist exist. The Heart Failure Association of the European Society of Cardiology</p>

				<p>position statement lists triggers for referral. The variables listed include clinical, laboratory, imaging and risk score data; they are all relevant prognostic variables, but many are non-specific and/or subjective. The variables should perhaps be seen as general markers of deterioration rather than distinct referral criteria. A pragmatic approach, such as using the five risk factors or a patient being highly symptomatic despite the best care as referral criteria could increase the number of referrals.”</p>
<i>Western Pacific</i>				
Driscoll et al., 2006 ²⁸	Cross-sectional study	N=4,450 from 33 HF clinics in Australia	Descriptive characteristics of HF clinics	Most of the clinics were located in metropolitan areas with only 21% in rural areas. Main mode of admission was through hospital admissions.
Driscoll et al., 2011 ⁴⁰	Prospective cohort study	N=1,157 from 55 HF clinics in Australia	Baseline characteristics of patients	78% of clinics had developed referral criteria. Participants in

			participating in HF clinics.	these cohorts were older, had multiple comorbidities, and presented mainly with ischemic HF
Palmer et al, 2019 ⁵⁸	Mixed-methods study	N=165 Australian clinicians working in outpatient HF clinics	Referral to HF clinics.	Referral sources included acute care, cardiologists, community nursing, allied-health officials, direct self-referral, and general practitioners. Barriers to attendance included poor condition-specific health literacy, lack of medical professional support, and interrupted health care systems.

HF= Heart Failure, NYHA= New York Heart Classification, PCI= Percutaneous coronary intervention, CABG= Coronary Artery Bypass Graft, N/A= Not Applicable, LVEF= Left Ventricular Ejection Fraction

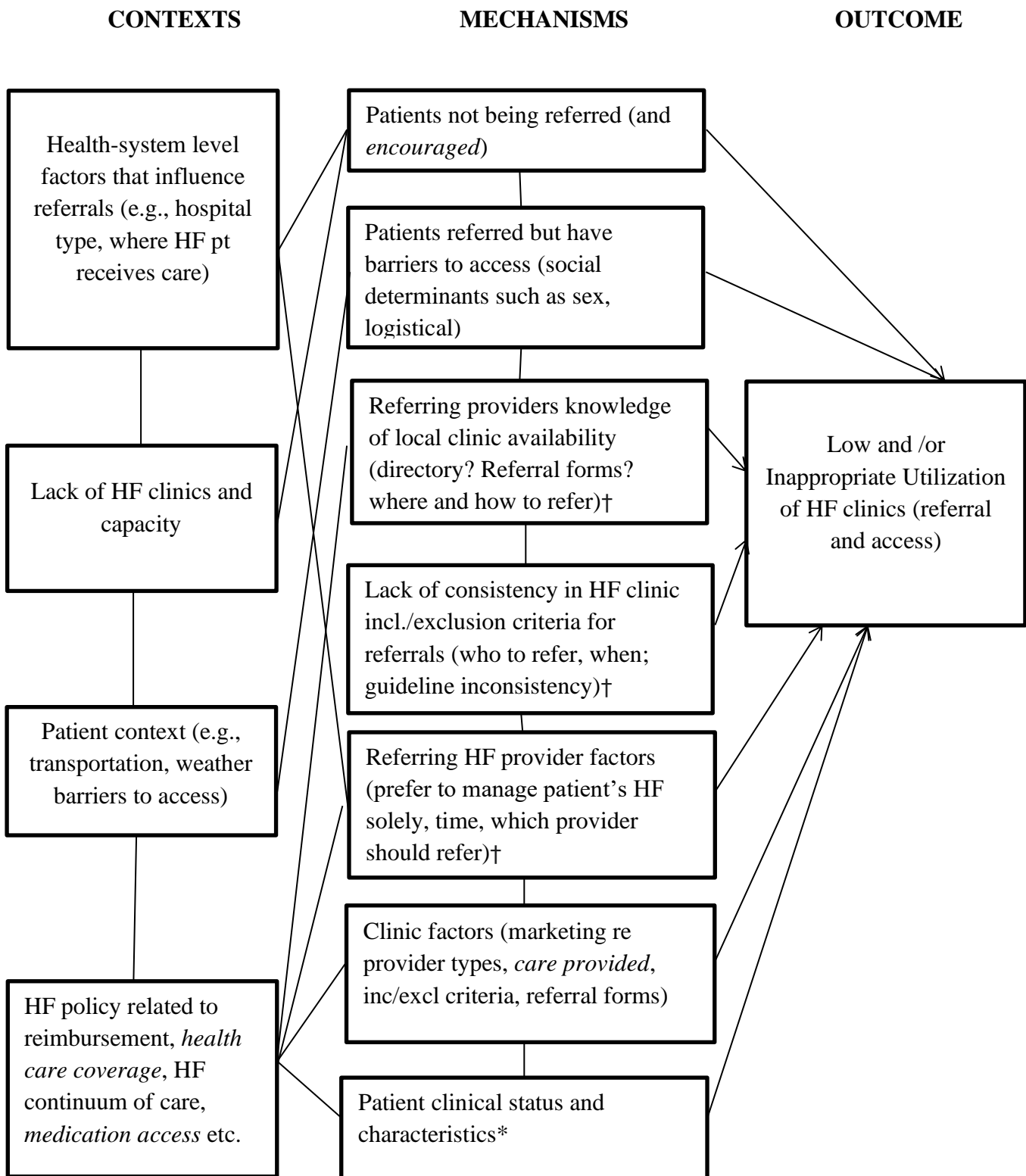
Figure 1: Context-Mechanism-Outcome Program Theory (with refinement)

†no evidence found related to this content

Note: text in italics was revised based on review

Figure 2 – Process of Paper/Report Identification

Figure 1: Context-Mechanism-Outcome Program Theory (with refinement)



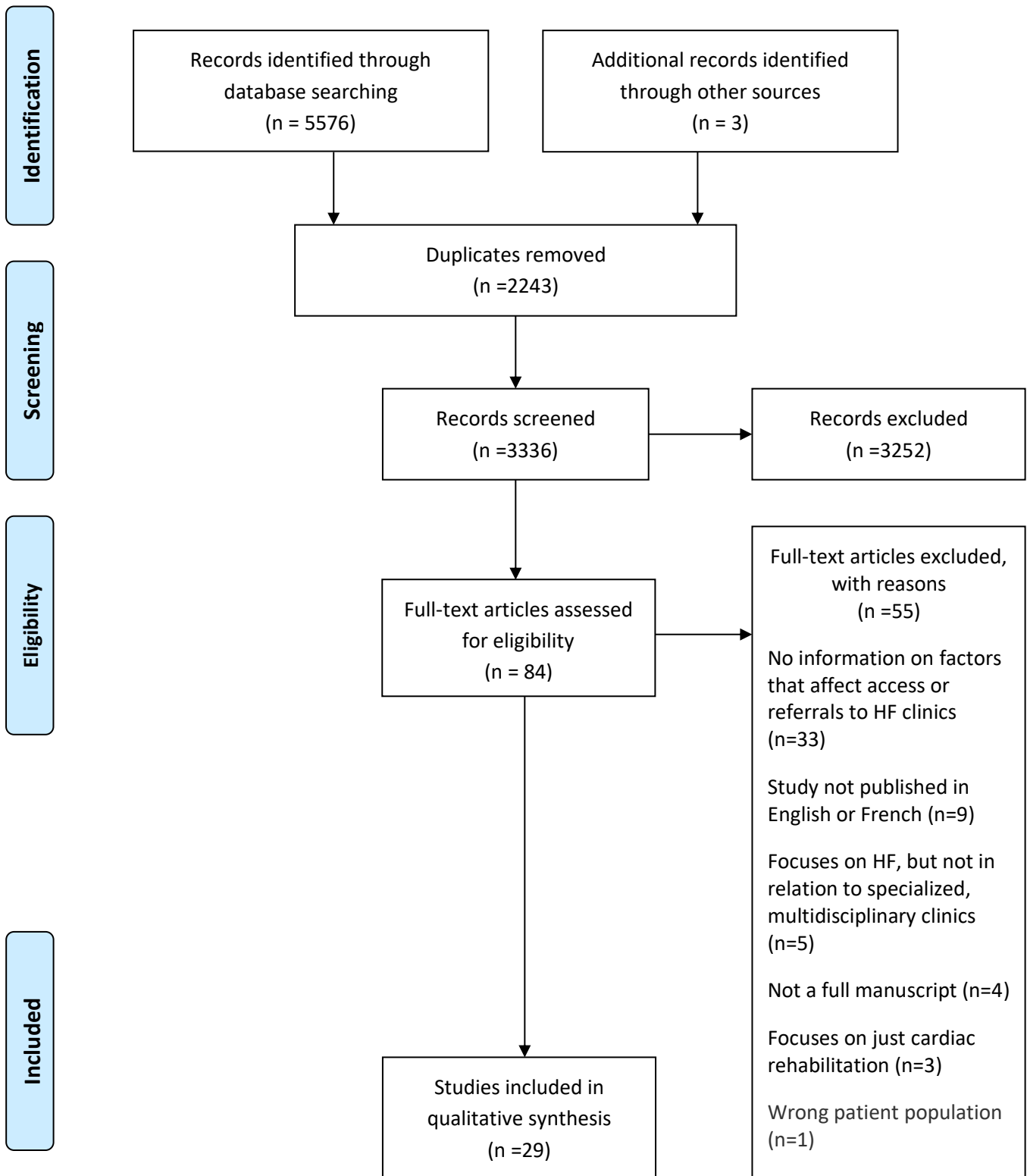
†no evidence found related to this content

Text in italics was refined based on review.

*these factors impact provider propensity refer due to differences in clinical presentation or unconscious bias for example, and raise patient barriers to attending appointments.

Arrows: There are 3 main C-M-O configurations: (1) low physician referral, whereby contextual factors at the health system level and lack of HF clinics and capacity lead to patients not being referred; (2) low patient access, whereby a patient is referred but their context is such that they have barriers to attending; and (3) inappropriate patient referral, whereby HF policy interacts leads to mechanisms for clinics and referring providers themselves, so patients who are not indicated are referred to a clinic (e.g., the patient has a new HF diagnosis, and emergency room physician cannot identify specialist for patient, so refers patient to a clinic in a quaternary centre).

Figure 2 – Process of Paper/Report Identification



Online Supplemental Table 1: Steps in the realist review based on Pawson *et al.* (2005)

Realist review steps	Summary of steps
Clarify Scope	An expert committee was convened to help determine the scope of the review and create the initial program theory. This realist review sought to identify mechanisms and underlying processes that influence utilization (appropriate referrals and access) to HF clinics globally.
Search for Evidence	A search strategy guided by the initial program theory was developed in consultation with an information specialist. In addition, a purposive grey literature search was conducted using websites that focus on the intervention being addressed by this study.
Appraise primary studies and extract data	All identified studies were reviewed for relevance and rigour. A data extraction tool was then used to obtain information from relevant, included studies on: study design and sources of bias; study characteristics (e.g., type of participants recruited, age range where applicable, study objectives etc.; the previous two were used to appraise rigour); country where the study was conducted, and information relevant to our program theory.
Synthesize evidence and draw conclusions	Evidence synthesis was guided by the program theory. We sought to explore potential C-M-O relationships by geographical region to understand variations in potential mechanisms that influenced HF clinic referral and access.

C-M-O: Context-Mechanism-Outcome

Online Supplement Table 2

Medline Search Strategy

Search Strategy: Ovid MEDLINE(R) ALL <1946 to December 05, 2019>

- 1 exp Heart Failure/
- 2 (failure adj4 (heart or cardiac or myocardial)).tw,kw.
- 3 ((decompensati* or incompetence or insufficien*) adj3 (heart or cardiac or cordis or cardis or myocardial)).tw,kw.
- 4 or/1-3
- 5 Outpatient Clinics, Hospital/
- 6 Cardiac Rehabilitation/
- 7 (clinic or clinics).tw,kw.
- 8 (rehab* and heart failure).tw,kw.
- 9 (heart failure adj3 refer*).tw,kw.
- 10 or/5-9
- 11 "Referral and Consultation"/
- 12 Health Services Accessibility/
- 13 Gatekeeping/
- 14 Secondary Care/
- 15 Tertiary Healthcare/
- 16 (refer* or access*).tw,kw.
- 17 ((secondary or tertiary) adj3 (health care or healthcare or service*)).tw,kw.
- 18 or/11-17
- 19 4 and 10 and 18
- 20 limit 19 to "humans only (removes records about animals)"