

**Using Intersectionality Theory and Critical Realism for Exploring Heart Failure  
Telehealth Interventions for Vulnerable Patient Populations: A Scoping Review,  
Intersectionality-based Analysis, and A Rapid Realist Review**

by

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## **Abstract**

**Background:** Heart Failure (HF) is at epidemic levels among older adults, globally. Heart Failure Disease Management Interventions (HFDMIs) enhance self-care and quality of life as well as reduce hospital readmissions, through patient education and follow up, effective treatment, psychosocial support, and enhanced access to care. Over the last two decades, telehealth is widely applied to HFDMIs. HF telehealth interventions are complex with multi-layered complexity attributed to the telehealth technology as well as to the complex patient population of frail older adults suffering with HF. Another layer of complexity is added when HFDMIs are developed and implemented for vulnerable patients with intersecting social identities. Critical realism (CR) with its explanatory focus serves as the most appropriate philosophical underpinning for intersectionality-based research, uncovering the underlying structures of power that give rise to health inequities in HF care.

**Purpose:** This dissertation is aimed at utilizing the meta-theory of CR to ground intersectionality-based HF telehealth research with vulnerable groups of HF patients.

**Methods:** This literature synthesis utilized a scoping review to map the existing body of literature around HF telehealth interventions for marginalized patient populations (such as racialized minorities, rural patients, gender minorities, poor or deprived etc.). The studies that were retrieved as a result of the scoping review, then went through an intersectionality-based analysis utilizing an intersectionality-informed checklist by Ghasemi et al., 2021. This intersectionality-based analysis was meant to identify the extent to which intersectionality has been applied to this body of research. Lastly, a rapid realist synthesis was undertaken for the same body of literature to explore the underlying mechanisms and contexts that make HF telehealth interventions work or not work for marginalized groups of HF patients.

**Findings:** A total of 22 studies were selected to be included in this review. As per the quality appraisal, the overall body of studies included in the review was of high quality. Most included studies were conducted in USA. Only two studies have employed qualitative methods and one study has utilized mixed methods. A few specific populations have been involved in most studies as participants, such as, African Americans, Hispanics, and rural low-income populations. The review findings demonstrate that though the principles of intersectionality have been applied to the stages of problem identification and intervention development and implementation; however, very few studies have applied these principles at the stage of intervention evaluation. Very few studies included in the review involved stakeholders including vulnerable populations as part of the problem identification and implementation of the intervention. Only six out of the 22 studies in this review had a measure of success based on reducing health inequities. The realist review findings indicate that vulnerable patients require simple interventions that can be easily adopted by them. The findings also suggest that for effective utilization of telehealth and remote monitoring services, these patients require simplified training that could increase their confidence in using this technology effectively. The review findings have also demonstrated that involving patients' family members in the delivery of telehealth interventions ensures success, especially when it pertains to the vulnerable groups such as racialized minorities and rural populations. This review has highlighted the fact that most telehealth programs are offered at large academic medical centres; whereas, typical heart failure patients, especially the vulnerable groups of HF patients mostly present at primary care clinics in community settings.

**Conclusion:** In conclusion, the findings from this scoping review suggest that the research around HF telehealth interventions for vulnerable populations is not adequately grounded in appropriate philosophical and theoretical underpinning. The principles of intersectionality have

been applied mostly to the problem identification and the intervention development and implementation stages, and not so much at the evaluation stage. Future research with vulnerable populations should be underpinned by the critical/ intersectionality theory, and should apply the principles of intersectionality at all stages of the research process, including evaluation and analysis. This review also urges HF practitioners to apply the principles of intersectionality and health equity in clinical practice, such that the interventions are simple, personalized, involve family members, include an in-person component, include patients' and health professionals' training, and integrate telemonitoring data in care team's work flow.

## Preface

This thesis is an original work by Saleema Allana. This research project and the resulting thesis was co-supervised by Dr. Alex Clark and Dr. Colleen Norris; both of them have had significant contributions to this dissertation in terms of its conceptualization, feedback on the process of data collection and analysis, and feedback on various parts of this dissertation. Dr. Justin Ezekowitz served as a committee member for this dissertation and he provided feedback at various stages of the dissertation as well. The data collection and analysis (as detailed in manuscript 5) as well as the introduction and the discussion chapters are my original work.

The four published manuscripts that follow immediately after the introduction chapter set the stage for this dissertation in terms of the theoretical underpinning as well as the literature review.

These are as follows:

1. Allana, S., & Clark, A. (2018). Applying meta-theory to qualitative and mixed-methods research: A discussion of critical realism and heart failure disease management interventions research. *International Journal of Qualitative Methods*, 17(1), 1609406918790042.

I and Dr. Alex Clark conceptualized this and wrote this manuscript. Dr. Clark provided feedback on the initial draft, I incorporated the feedback and submitted the manuscript, received and incorporated the feedback by the reviewers.

2. Allana, S., Thompson, D. R., Ski, C. F., & Clark, A. M. (2020). Intersectionality in heart failure self-care: Ignorance is not an option. *Journal of Cardiovascular Nursing*, 35(3), 231-233.

3. Allana, S., Ski, C. F., Thompson, D. R., & Clark, A. M. (2021a). Intersectionality and heart failure: What clinicians and researchers should know and do. *Current Opinion in Supportive and Palliative Care*, 15(2), 141-146.
4. Allana, S., Ski, C. F., Thompson, D. R., & Clark, A. M. (2021b). Bringing Intersectionality to Cardiovascular Health Research in Canada. *CJC open*, 3(12 Suppl), S4.

The above three manuscripts were conceptualized by Dr. Clark and I. I wrote the manuscripts, with some parts written by Dr. Ski, Dr. Thompson, and Dr. Clark. All of the three co-authors provided feedback; I incorporated the feedback, submitted the manuscripts, received and incorporated the feedback by the reviewers.

The fifth manuscript (submitted) presents the methods and the findings of the scoping review, intersectionality-based analysis, and the rapid realist synthesis. I was responsible for the data collection and analysis as well as the manuscript composition. Armish Hussain helped with the screening process as part of the scoping review. Dr. Alex Clark and Dr. Colleen Norris were the supervisory authors and were involved with the conceptualization and manuscript composition.

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## Table of Contents

<b>Chapter 1: Introduction</b> .....	1
<b>Background of the Issue</b> .....	1
<b>Context of the Issue</b> .....	7
<b>Meta-Theoretical and Theoretical Underpinning of the Research</b> .....	10
<b>Rationale and Significance of the Dissertation</b> .....	16
<b>Objectives for the Dissertation</b> .....	17
<b>Overview of the Dissertation and the Link between Manuscripts</b> .....	18
<b>Background Literature</b> .....	19
<b>Definitions of Important Terminologies</b> .....	19
<b>References</b> .....	21
<b>Chapter 2: Philosophical Underpinning- Critical Realism</b> .....	29
<b>Manuscript 1</b> .....	29
<b>Chapter 3: Literature Review- Intersectionality and Heart Failure Care</b> .....	39
<b>Manuscript 2</b> .....	39
<b>Manuscript 3</b> .....	43
<b>Manuscript 4</b> .....	50
<b>Chapter 4: Methods and Results</b> .....	56
<b>Manuscript 5</b> .....	56
<b>Chapter 5: Discussion</b> .....	110
<b>Overview of Main Findings with Discussion</b> .....	110
<b>Manuscripts and the Links between Those</b> .....	110
<b>Key Insights</b> .....	112
<b>Strengths</b> .....	112
<b>Limitations</b> .....	114
<b>Recommendations</b> .....	114
<b>Conclusion</b> .....	116
<b>References</b> .....	118
<b>Bibliography</b> .....	119

## **List of Tables**

Table 1: Characteristics of Included Studies ..... 71-74

Table 2: Synthesis of Application of Intersectionality in Included Studies..... 75

## **List of Figures**

Figure 1: PRISMA Diagram .....	69
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## **Chapter 1: Introduction**

### **Background of the Issue**

Heart Failure (HF) is at epidemic levels among older adults, globally (Piepoli et al., 2022). Heart Failure Disease Management Interventions (HFDMIs) enhance self-care and quality of life as well as reduce hospital readmissions, through patient education and follow up, effective treatment, psychosocial support, and enhanced access to care (Jaarsma et al., 2021; Zhao et al., 2021). Over the last two decades, telehealth is widely applied to HFDMIs. HF telehealth interventions are complex with multi-layered complexity attributed to the telehealth technology as well as to the complex patient population of frail older adults suffering with HF. Another layer of complexity is added when HFDMIs are developed and implemented for vulnerable patients with intersecting social identities. Critical realism (CR) with its explanatory focus serves as the most appropriate philosophical underpinning for intersectionality-based research, uncovering the underlying structures of power that give rise to health inequities in HF care. This dissertation is aimed at utilizing the meta-theory of CR to ground intersectionality-based HF telehealth research with vulnerable groups of HF patients.

HFDMIs are complex in nature. First, these interventions vary widely in type and context including interventions provided in-person in hospitals, communities or clinics, to those provided in the home remotely via telephone, email, internet or text messages (Jiang et al., 2021). These interventions are provided either by independent health professionals such as nurses or physicians, or by multidisciplinary teams; some interventions are delivered face-to-face, whereas others are delivered remotely (Takeda et al., 2019). In addition, HFDMIs are provided at various frequencies and over different time durations (Takeda et al., 2019). Secondly, most HFDMIs are focused on

different components including interventions focused on medication compliance, medication compliance, physical activity/ exercise training, improving patients' mental health, health education around diet, salt restriction, fluid/ alcohol restriction, weight management, and remote monitoring (Jiang et al., 2021). Thirdly, the outcomes of these interventions are composite outcomes generated by interactions between the intervention components and the 'context' of the intervention delivery (Allana & Clark, 2018). Given the presence of complex interactions within and around HFDMIs, and given their inherent complexity, it is essential to explore which 'contexts' and 'mechanisms' make HFDMIs interventions produce the best outcomes.

### **Telehealth HFDMIs**

Telehealth refers to the use of information and communication technology to deliver healthcare, so as to increase access, to improve outcomes, and to reduce the cost (World Health Organization, 2019). Over the last two decades, telehealth interventions have been widely applied in the context of HFDM (Athilingam & Jenkins, 2018; Gallagher et al., 2017). Telehealth interventions are meant to reduce hospital readmissions, reduce mortality, improve patients' quality of life, and empower them in relation to their self-care (van denBerg & Maeder, 2018).

The inclusion of telehealth in HFDM programs started with telephone support interventions in 1998 (Kotb et al., 2015). As new technologies were introduced, a new form of telehealth came into play, known as telemonitoring. Telemonitoring refers to the use of information technology to monitor patients at a distance, so that clinicians can intervene promptly if there are signs of worsening clinical condition (Nick et al., 2021). Telemonitoring revolutionized HF disease management, as long distance travel to the clinic was no longer required to monitor patients' symptoms and clinical status. With the advent of smart phones, disease management was further modernized and more importantly was now at the patients' fingertips (Athilingam & Jenkins,

2018). In recent years, technology has advanced even further with the introduction of video consultations for heart failure disease management (Gallagher et al., 2017). Today, the future of telehealth in cardiology is being redefined in the form of wireless monitoring of heart sounds through Bluetooth (Brites et al., 2021), which is yet another milestone in the application of telehealth to HFDMIs.

Since the initial introduction of telehealth in HF management, structured telephone support has been used for several purposes including: follow up, symptom monitoring, diet and medication counseling, maintenance of fluid status and physical activity (Nick et al., 2021; Silva-Cardoso et al., 2021). Different types of structured telephone support have been used. For instance, there are structured telephone support interventions with human to human contact (where the patient communicates with a nurse through the telephone) or human to machine interface (where the patient communicates with a machine or automated voice response system via telephone) (Takeda et al., 2019). The timing of the interventions also varied with some structured telephone support interventions being provided 24/7, whereby patients could call a nurse anytime, or the interventions were restricted to telephone support only available during office hours (Takeda et al., 2019).

With the passage of time, new technologies were introduced that broadened the horizon of telehealth HFDM. One such technology, which revolutionized physiological monitoring, and increased HF patients' access to health professionals, is remote monitoring (Bashi et al., 2017). Remote monitoring refers to the remote transmission of physiological data, such as, heart rate, blood pressure, weight etc. (Mathew et al., 2018). It provides the opportunity for monitoring patients' physiological measures at home, and ensures quick transfer of this data to nurses and physicians. This technology utilizes automated machines that are connected with computer

systems. This means that as soon as the patient weighs themselves or checks their heart rate, the data is transferred remotely to care providers (Bashi et al., 2017). Telemonitoring interventions have been shown to be effective in reducing mortality (Risk Ratio 0.66 95% CI 0.54-0.81,  $p < 0.001$ ), and HF related hospitalizations (Risk ratio 0.72, 95% CI 0.61-0.85), and in improving patients' quality of life (Bashi et al., 2017).

Mobile phone-based monitoring is another form of telehealth interventions, that is delivered through mobile apps. A recent review found about 26 mobile Health apps that are specifically being used to ensure self-care among heart failure patients (Athilingam & Jenkins, 2018). These apps help in achieving the specific components of heart failure self-care including symptom assessment, weight and blood pressure monitoring, electrocardiogram monitoring, medication management, cues for action, psychosocial health, tracking physical activity. These apps not only help in monitoring, but have demonstrated effectiveness in behavior change through strategies such as constant reminders (Athilingam & Jenkins, 2018). Given that mobile phones are typically close at hand throughout the day, these apps are also accessible for patients.

The next major advance in technology to support HF patients is video monitoring and consultations. Gallagher et al. (2017) tested a video consultation intervention for heart failure patients at the St. Vincent's hospital, UK. A majority of the patients rated the video conferencing very positively, especially as it saved on long distance travel and time, however a few reported connectivity concerns. Issues related to data protection and confidentiality were discussed by the participants as well. Physicians reported increased confidence, broadening of knowledge base, and a perception of improved patient outcomes (Gallagher et al., 2017). Although video consultations were utilized for the patients living in remote and rural areas even before the pandemic; however,

amidst the pandemic, video consultations have been widely used for HF patients, and these have resulted into immense patient satisfaction (Barkai et al., 2021).

The recent introduction of Bluetooth yielded a new technology in telehealth for cardiology patients. This has been reported as the future of telecardiology (Brites et al., 2021). A smart digital stethoscope system can monitor patient' heart sounds, and can identify abnormalities such as murmurs, in real time (Chowdhury et al., 2019). This system utilizes wireless Bluetooth for communication. The system consists of: 1) a portable digital stethoscope that captures and sends the heart sounds to the computer wirelessly, and 2) a computer-based decision-making system, which determines if the heart sounds are normal or abnormal (Chowdhury et al., 2019). It has been suggested that this technology will take telehealth in cardiology to a new level, where specialized assessments can be made using technology, and can be transmitted wirelessly.

### **Complexity in Telehealth HFDMIs**

In terms of complexity, interventions can be classified as either simple, complex, or complicated (Clark, 2013). Simple interventions can be as simple as following a recipe, which is already tested and produces standardized results each time (Rogers, 2008). A complicated intervention can be understood with the example of sending a rocket to the moon, which requires accurate formulae, a high level of expertise, and precedence, all of which assure a certain and successful outcome (Clark, 2013). However, complex interventions are different than simple and complicated interventions. Complex interventions can be best exemplified through the example of raising children (Clark, 2013). No one formula works in raising a child, neither past successful experience nor expertise guarantees future success. Every child is unique and a myriad of factors are involved in parenting, therefore, no fixed approach definitely works, rather each time a tailored approach is required as per the uniqueness of the child and considering all of the

contextual factors involved (Clark, 2013; Rogers, 2008). Complex interventions are composed of components, which work together in a non-linear fashion. The intervention takes place within the nested systems, which affect the delivery and outcomes of the intervention (Clark, 2013).

Accordingly, HF telehealth interventions are characterized by various components (example: telephone support, telemonitoring, patient education etc.) that work simultaneously to produce the intended outcomes. These interventions work within the broader health care and social systems, and their delivery and outcomes are affected by the interactions with these nested systems (Allana & Clark, 2018). Thus, there is an inherent complexity in HF disease management and telehealth interventions.

From their inception, HFDMIs have been complex in terms of the types of interventions and the intervention components (Savard et al., 2011). The HF population, for which HFDMIs are planned, further adds to the complexity of these interventions. For example, the average age at HF diagnosis is 76 years (Moertl et al., 2017), an age that is also associated with frailty makes HF care more complex (Ezekowitz et al., 2017). Frailty leads to many issues in patients with HF, including: susceptibility to the side effects of multiple drugs, orthostatic hypotension, and falls; moreover, many older adults with HF develop other medical, cognitive impairments and geriatric syndromes, which further deteriorate their self-care capacity, functional status, and quality of life (Ezekowitz et al., 2017).

Telehealth was reportedly meant to reduce the complexity around HF and its management (Kvedar et al., 2014). However, telehealth interventions are immensely complex in themselves, particularly as they transform the existing health care delivery models (Alami et al., 2018). Alami et al. report that for a telehealth intervention to be successful, multiple factors including the political will, organizational, clinical, administrative and technological leadership at different

levels must be addressed (Alami et al., 2018). Furthermore, patient preparedness and acceptance of technology is another important factor that adds to the complexity of telehealth interventions (Alami et al., 2018). For both care providers and patients, switching from traditional modes of care delivery to telehealth is complex, as it involves changes in organizational culture, mode of service delivery and practices (Alami et al., 2018). Thus, telehealth HFDMIs are complex interventions that need to be studied accordingly. This includes understanding HFDMIs within the context of the intersectional nature of people being treated for HF.

### **Context of the Issue**

#### **Heart Failure Telehealth Interventions for Vulnerable Patient Populations**

Vulnerability is a concept that has some subjectivity in the way it is conceptualized; therefore, it is almost always a contested notion as to what contributes to vulnerability in people. There are several definitions of vulnerability; some of these represent vulnerability as a universal condition, whereas, some relate it to a particular attribute/s that might lead to vulnerability (Barrett et al., 2016). In the context of health research, as well, vulnerable populations have been defined in various ways. Webber-Ritchey et al. (2021) define vulnerable populations as the ones who are at a risk of poor physical, mental, and social health. Stowell et al. (2018) further narrow it down by specifying the personal characteristics that lead to vulnerability including low socioeconomic status, belonging to a racialized or ethnic minority group, which lead to significant barriers to a healthy lifestyle. On the other hand, Moll et al. (2020) describe vulnerability as a state that is not a result of personal characteristics, rather, they deem it to be an outcome of social and systemic barriers, such as, poverty, illiteracy, language barriers, and the discrimination that is encountered by a person due to their gender, ethnicity, age, or disability. However, the most comprehensive definition of vulnerable populations has been provided by

Parker et al. (2018); they include indigenous peoples, immigrants and refugees, racialized minorities, unemployed, low-income, people who are homeless or who use public housing, and those living in rural/ remote areas as vulnerable populations. Finally, the American Heart Association (AHA) has drawn its definition of vulnerability in the context of HF care through the Vulnerable Populations conceptual Model that emphasizes on the access to socioeconomic and environmental resources, which determines people's vulnerability. As per White-Williams (2020), HF patients are already vulnerable and increasing self-care demands increase their vulnerability.

Vulnerability increases with intersecting social identities. For example, HF patients with intersecting social identities are more vulnerable as compared to other HF patients i.e. they are at an increased risk for worsened health and social outcomes, due to the various health and social inequities that they experience (Allana et al., 2020). The intersecting social identities, such as, sex, gender, ethnicity, rurality, indigeneity, and disability give rise to adverse outcomes in HF through some mechanisms, which have been highlighted by the White-Williams (2020). These mechanisms include: healthcare coverage, access to resources and relevant high-quality care, health literacy, and social support. For instance, rural HF patients who belong to low socioeconomic status have decreased access to resources and health care services. Similarly, HF patients who are from specific racialized minorities or Indigenous communities may have lower levels of health literacy or social support. Likewise, new immigrants or refugees might not have healthcare coverage for all of the health services required for HF management. Thus, intersectionality deepens and widens health related disadvantage and subsequently leads to adverse health outcomes.

Another layer of complexity is added when telehealth interventions are designed or implemented for HF patients from vulnerable groups. This complexity is due to the various intersecting social identities that may lead to either a lack of access to, or challenges in utilization of telehealth services. It has been noted worldwide that amidst the COVID19 pandemic, telehealth compared to traditionally delivered care was preferred by many patients (Bhatia et al., 2021), and due in part to the ease of access would likely remain the preferred mode of care post pandemic (Bhatia et al., 2021). However, it has also been observed that marginalized and underserved populations have faced significant barriers in accessing and utilizing telehealth amidst the pandemic (Shaw et al., 2021). Studying the available literature in-depth, identified three distinct issues that limit our understanding of HFDMIs in vulnerable populations. First, there is a dearth of studies that have explored telehealth interventions among vulnerable/marginalized groups of HF patients. Secondly, in the few studies addressing this issue, most have only explored a single intersectional characteristic of the sample, such as ethnicity, rurality, or social class, and report on how a single characteristic affects the access to or utilization of HF telehealth interventions (Allana et al., 2021b). These studies are therefore unable to integrate intersectionality in HF care research; intersectionality seeks to explore the health inequities experienced by vulnerable groups of HF patients, who carry multiple intersecting social identities (Al-Faham et al., 2019; Hankivsky et al., 2009). This is problematic because in the absence of an intersectional lens, the cumulative disadvantage that is brought about by a complex intersection of social identities and the resulting power dynamics, cannot be explored (Allana et al., 2021b). Lastly, in order to address the inherent complexity of HF telehealth interventions, which is augmented by the complexity involved in dealing with marginalized patient populations, such a research approach is needed that can not only explore

the complex interactions involved BUT more importantly uncover the ostensibly invisible mechanisms and contexts that will result in better outcomes for patients with HF (Allana & Clark, 2018).

In 2000, the Medical Research Council (MRC) recognized the complexity of disease management interventions and published their first guidance regarding the development and evaluation of complex interventions (Campbell et al., 2000); MRC prescribed an upgraded guidance around developing, evaluation, and implementing complex interventions in 2021 (Skivington et al., 2021). THE MRC guidance recognizes the sources of complexity in complex health interventions, and thus suggests the use of a complexity approach in the development, implementation, and evaluation of complex interventions (Skivington et al., 2021). Looking at the complexity of HF telehealth programs for marginalized patient populations, a theoretically and philosophically sound underpinning is required to guide research in this area.

### **Meta-Theoretical and Theoretical Underpinning of the Research**

This dissertation is underpinned by the critical realist (CR) ontology and intersectionality theory.

#### **Critical Realism- The Worldview that Guides this Dissertation**

Ontologically, CR proposes the three interconnected layers of reality, that is, the real, actual, and the empirical (Schiller, 2016). The *real* domain is comprised of the underlying mechanisms that have the potential to generate observable or unobservable events in the realm of the *actual*; therefore, these mechanisms can explain the occurrence of events (Schiller, 2016). These causal mechanisms exist and operate independent of the human perception (Bhaskar et al., 1998). In the *actual* domain, events occur, irrespective of whether or not these are perceptible by humans (Schiller, 2016). This means that there are many events taking place in the realm of the *actual*, among which only few can be perceived or experienced by us (Schiller, 2016). The perceptible

events are all part of the *empirical* domain; these are the only events that humans are capable of perceiving, and thus, these are the only phenomena that can be explored through scientific research (Allana & Clark, 2018; Bhaskar et al., 1998). Since only a few observable events can be captured by the methods of scientific inquiry, scientific claims are almost always fallible (Allana & Clark, 2018; Bhaskar et al., 1998). Observable *events* and *outcomes* are the result of underlying *mechanisms*, which are the intended or inadvertent resources created by an intervention and the response to those resources (cognitive, emotional, or motivational) by the participants (Dalkin et al., 2015). Operating under this ontology, research based on CR focuses on explaining health and social outcomes via these mechanisms and contexts (Allana & Clark, 2018).

*Explanations are at the heart of critical realism.* CR's main focus is on *explaining* the outcomes that are produced in the *empirical* and *actual* domains, by exploring the underlying mechanisms existing in the realm of the *real* (Pawson & Tilley, 1997). Therefore, CR appropriately underpins the research questions related to 'why' phenomena occur (Allana & Clark, 2018). In intervention research, this means moving beyond measuring effectiveness i.e. whether an intervention works or not, to understand *why interventions work or not* (Pawson & Tilley, 1997).

*Generative logic of causality.* The hallmark of CR is its generative logic, which is opposite to the successionist causality, a characteristic feature of positivism (Allana & Clark, 2018). A successionist approach to causality implies a linear approach, which suggests that an intervention produces a particular outcome, without any reference to the context in which the intervention occurs, or the mechanisms through which its effects are produced (Allana & Clark, 2018; Pawson & Tilley, 1997). This approach is useful for the experiments in physical science, where experimental controls are in place; however, it does not work for complex health interventions, which are applied in social contexts, that cannot be artificially controlled (Pawson & Tilley, 1997).

In comparison to successionism, critical realism's *generative model of causation* suggests that social and health interventions are rooted in complex socio-cultural contexts, and their interplay with a multitude of factors associated with the people providing and receiving the intervention, the place(s) in which the intervention is provided, and the components and mechanisms of the intervention, cumulatively generate outcomes for these interventions (Allana & Clark, 2018; Pawson & Tilley, 1997). Subsequently, a health or social intervention alone, without any reference to its context, cannot be deemed effective or ineffective. Therefore, studies underpinned by CR should explore the wide range of individual, intervention related, and contextual factors associated with the intervention effects (Allana & Clark, 2018).

*Interplay of agency and structures to produce outcomes.* Having described above, the generative model of causation as one of the fundamental premises of critical realism, it is important to articulate that CR puts forward the notion of an interplay between *agency* and *structural* factors that can influence and explain outcomes (Clark et al., 2008). *Agency* refers to the internal factors to an individual such as attitudes, beliefs, and values, and *structures* imply external contextual factors such as cultural and social norms, places or structures (Allana & Clark, 2018). CR proposes that events or outcomes occur because of an interplay between individual factors such as attitudes, beliefs, and values, and contextual factors such as social processes, cultural norms etc. (Allana & Clark, 2018; Clark et al., 2008). This has important implications for HF care research, which must explore a wide range of individual and contextual factors, in order to determine from a critical realist perspective, as to *what influences outcomes from a HFDMI?* (Allana & Clark, 2018).

*An open system approach with multi-factorial causation.* CR presents an *open system* approach in contrast to the closed system approach that dominates both the physical sciences and randomized control trials (RCTs) (Pawson & Tilley, 1997). In physical science, *regular, law-like outcomes* are

generated by creating an artificial and experimentally controlled context in RCTs. Context is either controlled for or irrelevant in the closed system, thus, interventions are assumed to be inherently effective or ineffective (Pawson & Tilley, 1997). Whereas, CR, which primarily explores phenomena in social sciences, proposes that social change takes place or social programs work (*outcome*), when the programs (*interventions*) are undertaken with appropriate people (*patients, professionals*) through appropriate causal pathways (*mechanisms*) in conducive social and cultural conditions (*context*) (Allana & Clark, 2018; Clark et al., 2008). These factors can influence each other and the intervention, in generating powerful effects on outcomes (Clark, 2013). Thus, interventions that are found to be effective in one setting may not be as effective in another setting because outcomes do not just depend on the nature of interventions, but also the people involved and aspects of the context (Allana & Clark, 2018; Clark, 2013). Therefore, research adopting this open systems approach should explore the nature of interaction of these multiple factors, so as to know *what (intervention) works best for whom (populations), and how (mechanisms)?* (Pawson & Tilley, 1997).

With its explanatory focus, multi-factorial causation approach, and an emphasis on agency and structures, CR helps identify the underlying power structures that lead to health inequities in HF telehealth for vulnerable populations. Therefore, CR best complements the intersectionality theory and intersectionality-based HF telehealth research with vulnerable populations.

### **Intersectionality Theory- The Theoretical Underpinning:**

Intersectionality was first introduced as a concept that brought to light the various inequities experienced by women of color, with the aim of their emancipation and liberation (Crenshaw & Vistnes, 1989). It focused on how various intersecting social identities shape up or reinforce oppression (Crenshaw & Vistnes, 1989). Intersectionality theory proposes that oppression is

shaped through the sources of marginalization at both micro and macro levels. It highlights the cumulative effects of power or lack of power on the lives of marginalized individuals (Al-Faham et al., 2019). The greatest strength of intersectionality theory lies in the complexity and depth that it offers to analyze the instances of oppression and marginalization (Al-Faham et al., 2019). As a theory, intersectionality rejects the notions of essentialism, which proposes that an individual's experiences are shaped by one characteristic or identity such as gender or ethnicity, disregarding the other intersecting identities, as well as the contextual factors such as time, space, and systems that influence an individual's experiences greatly (Atewologun, 2018; Al-Faham et al., 2019).

As a research paradigm, intersectionality provides a framework of social justice-based analysis for exploring social problems that arise from an intersection of race, gender, class, sexual orientation, and other social identities (Hancock, 2007). Intersectionality-based research challenges the assumptions of within-group homogeneity and seeks to explore within-group variations that influence an individual's experiences and sets them apart from others in the same social group (Al-Faham et al., 2019). Intersectionality is one of the critical theories that “conceptualizes knowledge as situated, contextual, and relational” (Atewologun, 2018, p.1). Therefore, intersectionality is mostly associated with interpretive research, which provides a voice to the oppressed and marginalized to bring their experiences and perceptions to the surface (Atewologun, 2018). Nevertheless, intersectionality theory has been widely applied to quantitative research as well in the context of public health research (Bauer, 2014; Evans et al., 2018). However, for intersectional analysis to do justice with identifying the underlying power structures and social determinants, it is important that intersectionality-based quantitative research is underpinned by the theory. Mere application of interaction effects to regression

models, without any philosophical and theoretical underpinning, in an attempt to identify the ‘most risky’ identities, would not serve the very purpose of intersectionality-based analysis (Evans et al., 2018). Therefore, intersectionality-based research must embed intersectionality at all levels i.e. philosophical/theoretical, methodological, and analytical level.

### **How does Critical Realism Complement Intersectionality Theory:**

Critical realism and intersectionality theory have some commonalities, that has a lot to offer to health equity research. Both these theories/ philosophies are keen at exploring what lies beneath the surface of apparent and observable (Aspinall et al., 2019). Thus, CR can help identify the underlying power structures and mechanisms in the realm of the ‘real’ that cause oppression to occur in the realm of the ‘actual’, eventually getting evident in the realm of the ‘empirical’ (Aspinall et al., 2019). Understanding how and why oppression is shaped for marginalized groups of patients is essential for proposing and implementing appropriate changes in practice and policy pertaining to healthcare. While intersectionality theory helps in conceptualizing health inequities from the perspective of intersecting social identities, CR provides the tools that are necessary for uncovering the structures of power as well as the generative mechanisms that enact to shape experiences of oppression and inequities (Aspinall et al., 2019). CR is particularly useful as it recognizes that structures of power do lead to marginalization and oppression, whether or not it is observed, acknowledged, or recognized (Martinez et al., 2014). Thus, CR and intersectionality theory overlap in many ways, some important similarities are: a recognition that multiple factors (identities, social or power structures) intersect to produce or reinforce marginalization, and an acknowledgment of agency, that is, individual’s free will and potential to act against the structures of power (Martinez et al., 2014). Exploring underlying sources of racism, classism, sexism in healthcare, and how they lead to health inequities is extremely

important and can be done best through research underpinned by intersectionality theory and critical realism.

### **Rationale and Significance of the Dissertation**

Evaluation of telehealth interventions include not only the technological aspects, but also the socio-organizational and the environmental factors that affect these interventions (Lau & Kuziemsky, 2016). To date, several methods have been used to evaluate telehealth interventions, ranging from descriptive studies to randomized controlled trials (RCTs), whereby the RCTS have mostly targeted the effectiveness of these interventions, and the descriptive studies tended to explore and understand the users' experiences (Lau & Kuziemsky, 2016). Moreover, economic evaluation methods have also been applied to telehealth interventions to examine the relationship between its cost and financial return (Lau & Kuziemsky, 2016).

Realist synthesis is a relatively new research approach rooted in the philosophy of critical realism, which seeks to explain how and why an intervention works or not for a particular patient population (Pawson & Tilley, 1997). As per the philosophy of CR, realist synthesis puts forward the notion of generative causation; this means that any intervention in itself is not effective or ineffective; rather, many contextual factors and underlying mechanisms play their part in making it successful or unsuccessful. Thus, realist synthesis seeks to uncover those contextual realities and underlying mechanisms (Pawson & Tilley, 1997). The realist approach has been utilized to evaluate telehealth interventions in some studies such as for medication safety and for self-management support interventions for people with chronic diseases (Jeffries et al., 2017; Vassilev et al., 2015). Recently, Clark et al. (2022) have undertaken a realist synthesis of remote monitoring programs for cardiac rehabilitation and secondary prevention. However, to date, no realist synthesis has been done for HF telehealth and remote monitoring interventions,

specifically for the marginalized groups of heart failure patients. Also, intersectionality-based analysis utilizing a structured checklist has never been done before for HF telehealth programs/ interventions. Therefore, this rapid realist synthesis along with an intersectionality-based analysis of the existing body of literature in this area, is the first of its kind and has produced novel findings that have the potential to significantly improve delivery of telehealth interventions to vulnerable/ marginalized groups of HF patients.

Knowledge synthesis approaches were chosen for this dissertation as the primary mode of investigation because the intent was to map the existing body of literature in the area of HF telehealth interventions for vulnerable populations. Having some sense of the literature in this area, I anticipated that not much has been done around vulnerable populations in this area; however, no one had ever mapped or synthesized this literature. The novelty of this study lies in the combination of scoping review methods with the realist review method and an intersectionality-based analysis, which helped in generating new and valuable insights. The integration of these three methods brought a health equity as well as a critical realist lens to HF telehealth interventions, which was a very unique combination, which resulted in unique findings.

### **Objectives for the Dissertation**

The purpose of this scoping review and literature synthesis is to:

1. Map the existing body of literature around HF telehealth interventions for marginalized patient populations (such as racialized minorities, rural patients, gender minorities, poor or deprived etc.)
2. Explore the extent to which intersectionality has been applied to this body of research, utilizing an intersectionality-informed checklist

3. Identify the underlying mechanisms, contexts, and outcomes that make HF telehealth interventions work or not work for vulnerable/ marginalized groups of HF patients, via a rapid realist review

### **Overview of the Dissertation and the Link between Manuscripts**

As described above, this dissertation is underpinned by the meta-theory of CR. Therefore, the first manuscript, which has been published in the *International Journal of Qualitative Methods* (Allana & Clark, 2018), explains in detail the philosophical assumptions of CR and how it relates to heart failure research. The dissertation then connects the theory of intersectionality with CR's philosophy that seeks to explain the observable health inequities experienced by individuals with intersecting social identities, through underlying mechanisms and contextual realities. Thus, the second and the third manuscripts, published respectively in the *Journal of Cardiovascular Nursing* (Allana et al., 2020) and the *Current Opinion in Supportive and Palliative Care* (Allana et al., 2021a), demonstrate the significance of applying intersectionality theory to practice and research in heart failure care. The fourth manuscript, published in the *Canadian Journal of Cardiology Open* (Allana et al., 2021b), takes it a step ahead in terms of providing practical guidance for cardiovascular researchers to apply intersectionality theory to cardiovascular research. This manuscript provides examples of research questions that can be explored through an intersectionality lens and provides methodological directions.

Based on the objectives, this dissertation has mapped the existing body of literature around HF telehealth interventions for marginalized populations through a scoping review. Secondly, this dissertation has explored the extent to which intersectionality has been applied to these studies, utilizing an intersectionality-informed checklist. Finally, through a rapid realist

synthesis, this dissertation has identified the relevant contexts and mechanisms that make these telehealth interventions work or not for the vulnerable/ marginalized groups of HF patients. The fifth manuscript presents a comprehensive account of methods and findings from the scoping review, intersectionality-based analysis, and rapid realist synthesis. This manuscript also presents important insights around how and why HF telehealth interventions work or not for the marginalized groups of HF patients. It also suggests recommendations to adopt intersectionality in HF telehealth research in its full essence, based on the intersectionality-based analysis that has been conducted as part of this dissertation.

### **Background Literature**

The background literature has been included in manuscripts 2, 3, 4, and 5.

### **Definitions of Important Terminologies**

There are some terminologies that are at the heart of this dissertation, and therefore those have been used frequently in this proposal, such as, vulnerable populations, intersectionality, contexts, mechanisms. In order to make these concepts clear for the readers, their definitions have been provided below. The terms programs and interventions are used interchangeably in the realist literature.

#### **Vulnerable**

Vulnerable populations are those that are more susceptible to disadvantage due to their belonging to a certain group, having a particular attribute or characteristics, or lacking a particular capacity (Wrigley & Dawson, 2016). In the context of this dissertation, vulnerable populations refer to racialized minorities, rural populations, gender minorities, patients with low income or low educational levels etc.

#### **Intersectionality:**

Intersectionality recognizes the various identities that each of us carries such as our: age, gender, sexual orientation, race/ethnicity, religion, social class, immigration status, place of residence (rural/ urban) etc., and how these identities intersect to bring about either oppression or privilege (Al-Faham et al., 2019; Hankivsky et al., 2009). In the context of this dissertation, we were specifically interested in health inequities experienced by HF patients from vulnerable groups and who have intersecting social identities.

### **Context**

Context refers to the pre-existing or prevailing social conditions in which programs or interventions are introduced, and it plays an extremely important role in the success or failure of a program (Pawson & Tilley, 1997). Context not only includes the physical space where the program is delivered, but it also consists of the social rules, norms, values, and interrelationships, which affect the program mechanisms (Pawson & Tilley, 1997). For this dissertation, we explored the contextual realities that made HF telehealth interventions work or not for vulnerable patient populations.

### **Mechanisms**

Mechanisms are the intended or inadvertent resources created by an intervention and the response to those resources (cognitive, emotional, or motivational) by the participants.

Mechanisms delineate as to why participants choose to or choose not to participate in the programs, or internalize the knowledge or behavior change from the program (Dalkin et al., 2015). For this dissertation, we explored the underlying mechanisms that made HF telehealth interventions work or not for vulnerable patient populations.

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## **Chapter 2: Philosophical Underpinning- Critical Realism**

### **Manuscript 1**

**Title:** Applying Meta-Theory to Qualitative and Mixed-Methods Research: A Discussion of Critical Realism and Heart Failure Disease Management Interventions Research

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# Applying Meta-Theory to Qualitative and Mixed-Methods Research: A Discussion of Critical Realism and Heart Failure Disease Management Interventions Research

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## Abstract

Meta-theory refers to broad perspectives, which make claims regarding the nature of reality. Meta-theories philosophically underpin research and practice. Despite this centrality of meta-theory to research and practice, research studies seldom have a strong articulated philosophical basis. There are persuasive philosophical arguments for invoking meta-theory in qualitative and mixed-methods research. We argue that selecting and applying a particular meta-theory is a matter of personal expression and historicity. In this article, we describe the meta-theory of critical realism (CR), which underpins our research around complex heart failure disease management interventions. CR posits that reality is mind independent and views this reality via a stratified ontology. Its explanatory focus, generative logic, multifactorial and open systems approach, and its openness to a variety of methods make it a viable meta-theory for research in a variety of disciplines, utilizing qualitative, quantitative, and mixed methods. CR hermeneutics, ethnographies, grounded theories, mixed-methods studies, and critical realist reviews follow the meta-theoretical assumptions of CR; these are extremely useful in exploring complex interventions holistically, including their components, contexts, and mechanisms.

## Keywords

meta-theory, critical realism, qualitative and mixed-methods research, complex intervention research, heart failure disease management interventions

## What Is Already Known?

Critical realism (CR) has been known as a meta-theory that underpins research and practice. Its assumptions of open systems, generative logic, agency and structure-related factors, and its methodological eclecticism have been widely acknowledged and appreciated. Health researchers have begun utilizing the meta-theoretical underpinning of CR.

## What This Paper Adds?

What is missing in the literature is how a meta-theoretical orientation is developed. This is the first article to present reflexive accounts of the authors as to how their meta-theory evolved, which would help novice researchers to reflect over their meta-theoretical orientation. In relation to CR, a gap persists in the literature as to how different research methods

operate under the meta-theory of CR. This article discusses in detail various qualitative methods, mixed methods, and critical realist reviews, underpinned by the assumptions of CR.

Applying meta-theory to qualitative research is important, yet challenging. This article illustrates how a meta-theory can be applied to qualitative and mixed-method research using the example of CR. The article will demonstrate for others, how to apply meta-theory to their work and appreciate more the nuances, compromises, and tensions in doing so.

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## Meta-Theories: What They Are and Why They Matter

Meta-theory refers to broad perspectives, which make claims regarding the nature of reality. Meta-theories overarch many other theories, notably mid-range theories. Well-known meta-theories include Marxism, constructivism, positivism, and postpositivism. As such, meta-theory addresses fundamental beliefs about the world that guide an individual's actions and can be termed to be paradigms or worldviews (Lor, 2011). Accordingly, meta-theories philosophically underpin research, practice, and substantive theory in any field of study (Sousa, 2010).

In qualitative methods, theory is a common concept invoked both in terms of types of knowledge that can be generated (notably through grounded theory) or to inform how phenomena are understood and to guide procedures around literature reviews, data collection, analysis, and knowledge translation. Meta-theory can also be used to underpin practice—for example, in relation to health care. The meta-theoretical orientation provides the health researchers with a particular ontology and epistemology, for investigating their research questions (Lor, 2011). Despite this centrality of meta-theory to research and practice, research studies seldom have a strong articulated philosophical basis (Prestwich et al., 2014). This raises the issue about how researchers can incorporate meta-theory in their research. Is invoking meta-theory in research a matter of personal expression or practical choice? How can and should meta-theory be expressed in the specifics of research? First, we will consider, is meta-theory necessary to be addressed in qualitative and mixed-methods research?

### Meta-Theory and Research: A Matter of Choice?

There are persuasive philosophical arguments for invoking meta-theory in qualitative and mixed-methods research. Aspects of our past and our real selves shape our lens of viewing the world, which leads us to relate well to a particular meta-theory. This argument, based on Heidegger's notion of historicity, views our past as uniquely attached to our "being" or our "self", and has the potential to influence our future choices (The Blackwell Dictionary of Western Philosophy, 2004). Therefore, it is extremely important for the researchers to be reflexive about their past experiences, their values, and beliefs, so that they can explore the meta-theory that best fits with their way of looking at the world. This article is the first to report the exploration of a meta-theoretical orientation by us as researchers; the article also illustrates how the meta-theory of CR guides qualitative and mixed-methods research around complex heart failure disease management interventions (HFDMIs).

It is important too, to specify the tenets of any particular meta-theory that one intends to use. While we frame our research around complex HFDMIs, CR appears to be the most appropriate meta-theory for underpinning our research, philosophically. To illustrate this, we will describe the philosophical

assumptions and key tenets of the meta-theory of CR. We then present our reflexive accounts in search of our own "historicity" that has led us to this meta-theoretical orientation. We then describe the philosophical underpinning provided by CR to shape our intervention research around HFDMIs. Finally, we discuss the qualitative and mixed methods that can be utilized to study complex HFDMIs, using the meta-theory of CR.

### CR and Its Outlook of Life

CR posits that reality is mind independent and views this reality via a stratified ontology which depicts three distinct but interconnected layers of reality, the realms of the real, actual, and empirical (Schiller, 2016). The *real* domain pertains to causal powers and potentialities that have the potential to generate observable or unobservable events in the actual domain. These underlying powers can explain events and outcomes in the world and they have existence and power independent of the human thought and awareness (Bhaskar, 1998). Mechanisms in the real domain are not directly observable but exist and can exercise power independent of human perception (Schiller, 2016). In the *actual* domain, events occur, whether or not these effects are experienced by humans. Events take place in the actual domain and have existence irrespective of whether these are perceived by humans (Schiller, 2016). The realm of the empirical refers to human perception and social processes, including seemingly formal inquires, such as scientific investigation and processes. Humans are only capable of inhabiting the empirical domain—and as such their claims to knowledge are always fallible, that is, these can never be certain (Clark, Lissel, & Davis, 2008).

To illustrate the ontological assumptions of CR, let us consider an example. For instance, an HFDMI designed for the HF patients resulted in improved clinical outcomes. Since improvement in clinical outcomes is a perceptible experience, this may be considered as a part of the empirical domain. Now, as per the CR ontology, though events are experienced in the realm of the empirical; however, they actually occur in the actual domain, whether or not these are perceived by humans. When this particular HFDMI was explored further, it was identified that it actually motivated the patients significantly to be compliant with their medications and prepared them well for continuous symptom monitoring and management. This was the event that probably occurred in the realm of the actual domain, and whether or not the patients were aware about this motivation and preparedness, it led them to take better care of themselves. Another assumption of the CR ontology suggests that all these events taking place in the actual and the empirical domains are a result of the causal mechanisms existing in the real domain. Process evaluation of this intervention revealed that the one-on-one communication of the health professionals with the patients, and their prolonged engagement, likely led to enhanced motivation and preparedness to deal with the symptoms. Thus, one-on-one communication of patients with health providers and prolonged engagement are the underlying

mechanisms that took place in the real domain, which led to motivation and preparedness of patients in the actual domain, eventually leading to observable improvement of clinical outcomes in the empirical domain.

## Key Tenets of CR

### *Explanatory Focus*

CR seeks primarily to explain outcomes—it is an explanatory ontology. This reflects the focus of CR primarily on aspects of the real—thus called, because powers and potentialities in the realm of the real exist and exert a real influence on outcomes in the realm of the actual, irrespective of whether this is known or not. Relatedly, CR is appropriate to explore research questions related to “why” phenomena occur. In intervention research, this means moving beyond merely measuring outcomes—whether an intervention works or not—to understand why interventions have the outcomes that they do. In short, why interventions work (Pawson & Tilley, 1997). As we will see, this is not only useful but also ontologically justified.

### *Successionism Versus Generative Logic*

CR views causality as being generative rather than, like positivism, successionist. A successionist approach to conceptualizing causality implies a linear approach, which suggests that *an intervention produces a particular outcome, without any reference to the context in which the intervention occurs or the mechanisms through which its effects are realized*. A successionist approach is more apt for the experiments in physical science where experimental controls are in place to exclude or control the numerous factors that can affect causality in a particular situation. However, given complex health interventions are delivered, enacted, and received in social contexts, these situations cannot be artificially controlled (Pawson & Tilley, 2001). In contrast to successionism, CR’s *generative model of causation* suggests that social and health interventions are always embedded in sociocultural contexts in which outcomes are generated by the complex interplay of factors associated with the people providing and receiving the intervention, the place(s) in which the intervention is provided, the components and mechanisms of the intervention (Clark, MacIntyre, & Cruickshank, 2007; Pawson & Tilley, 2001). Usually, small changes in one or more factors within this generative conception could lead to very large changes in outcomes. Subsequently, a health or social intervention alone, without any reference to its context, cannot be deemed effective or ineffective. Therefore, studies guided by the meta-theory of CR should seek to explore and account for the wide range of individual, intervention, and contextual factors associated with the intervention.

### *Explanations Rooted in an Interplay of Agency and Structures*

This generative model of causation posits that both agency and structural factors can influence outcomes (Clark et al., 2008).

*Agency* refers to the more microfactors that reside primarily in individuals; while, *structures* imply external contextual factors outside of individuals, such as cultural and social norms, places, or structures that may oppress particular groups, such as women, ethnic minorities, or those of low-socioeconomic status. CR proposes that events or outcomes occur because of an interplay between individual factors such as attitudes, beliefs, and values, and contextual factors such as social processes, cultural norms, and so on (Clark et al., 2008). This has important implications for social and health sciences research, which must explore a wide range of individual and contextual factors, in order to determine from a critical realist perspective, as to *what influences outcomes from an intervention?* (Clark et al., 2007).

### *Multifactorial Causation in an Open System*

Invoking agency and structural factors in this interplay and generating model yields an ontology that is natural, multifactorial, and multilevel. In short, it is complex. Pawson and Tilley (2001) label this conception to be that of an *open system—in contrast to the closed system* approach that dominates both the physical sciences and the randomized controlled trials. These closed system approaches assume that interventions have positive effects in accordance with *regular, law-like regulatives*. Interventions work or don’t work—and the benefits of interventions that work well in some setting should be transferable to other settings. This follows because context is assumed to be controlled for or irrelevant in the closed system, while interventions are assumed to be inherently effective or ineffective. Conversely, CR assumes an open systems approach in which context has the potential to influence outcomes, interventions are enacted in systems involving multiple factors associated with the intervention, context, and people involved. These factors can themselves influence each other in generating ways to be creative and unexpected but powerful effects on outcomes (Clark, 2012). Because systems are open, fluidity and change is usually common in these systems. Interventions that are found to be effective in one setting may not demonstrate similar benefits in another setting, because intervention effects don’t just depend on the nature of interventions, but also the people involved and aspects of context (Clark, 2012). Intervention research adopting this open systems approach should explore the nature of interaction of these multiple factors, as to know *what (intervention) works best for whom (populations), where (settings), and why (mechanisms)*.

### *Openness to Multiple Methodologies and Interdisciplinary Research*

Thus far, these tenets are ontological—referring to aspects of being rather than of method. Indeed, as a meta-theory, CR is more an ontology than methodology: It focuses primarily on the nature of reality and does not firmly prescribe how to capture or know that reality. A key benefit of CR associated with this primacy on ontology is in the meta-theory’s ability to

accommodate diverse research methods, notably qualitative and quantitative research, including mixed methods.

The explanatory focus, that defines CR, necessitates an openness to quantitative, qualitative, and mixed-methods data and study designs (Clark et al., 2008). Given reality is independent of the mind, different methods can be used to try to capture complexities of that reality—with the proviso that because the realm of the actual and real can never be truly known, all data (and indeed science) can only ever be seen as being an account of reality—and cannot be equated with reality itself.

CR research methods should be guided by the research questions and the complex phenomena being explored (Pawson & Tilley, 2001). This diversity in methods is due to CR's search for *explanations of outcomes in complex systems*, which requires various methods of data collection and analysis, to understand the dynamics of an array of contributing factors and mechanisms. As CR does not esteem any one data type over another (Clark et al., 2008), both qualitative and quantitative data can be used in CR inquiries.

Further still, given the primacy of reality to CR inquiry, the meta-theory implies that reality takes precedence over disciplinary positions—which may serve to distort, impoverish, or otherwise narrow accounts of reality (Sayer, 2000). As such, CR encourages researchers to focus on the complexity of the phenomena they are exploring beyond the disciplinary perspective(s) they may have (Clark et al., 2008). This is termed to be a postdisciplinary approach (Sayer, 2000).

### CR in Context

The two opposite philosophical orientations about the nature of reality have been positivism and constructivism. On the one hand, positivism claims for the absolute truth, regularities, and causal laws, whereas, on the other hand, constructivism argues for the reality which is relative to one's position within the social system (Cruickshank, 2012). CR found its way in between the two extremes of objective, mind independent and subjective, mind-dependent nature of reality assumed by positivism and constructivism, respectively. It assumes that the world is a stratified open system where unobservable events interact to produce the observable events (Cruickshank, 2012). The beauty of CR is in its assumption about the nature of reality, that is, though it assumes that the reality is mind independent, however, it also acknowledges the value of social explanation (Clark et al., 2008). Although the dual and sliding nature of CR's ontology has been critiqued (Cruickshank, 2004); however, this ontology makes CR adaptable for those who are interested in explaining the events, utilizing science and perceptions (Cruickshank, 2012). This means that CR can successfully accommodate the hermeneutical perspectives associated with constructivism and the mind-independent reality, traditionally ascribed to positivism (Elder-Vaas, 2012).

### Reflexivity for Explaining Meta-Theory Underpinning Our Research

Meta-theories should not only be ontologically defensible but should also be a product of the historicity of the researchers involved. For example, feminist researchers may ground themselves in this meta-theory because of personal, ethical, or practical reasons related to emancipation of women.

To clarify what this historicity looks like, in this section, we demonstrate as to how our personal selves (our past experiences, beliefs, and values) led to our meta-theoretical orientation.

#### Reflexive Account by Author I

For me, CR carries a deep meaning and a long history. I realized the importance of explanations at quite an early age. I remember being in a school initially, where knowledge was transferred to us to be remembered, but our *whys* were never attended to. As I moved to Grade eight, I fortunately got a teacher who knew the importance of answering the whys of her students. I distinctly remember her encouraging each of us, to not only get contented with the description of phenomena, rather, to go beyond and ask *why did this happen or why did this not happen?* Her encouragement to seek for explanations ignited my curiosity to understand every phenomenon in depth with its underlying mechanisms. As I grew up, I kept on looking for explanations of the phenomena encountered in everyday life, ranging from “why is it sunny some days and not on other days?” to “why are people settling out of the country so rapidly?”

Our meta-theoretical orientation is not only influenced by our personal values, but these are also shaped up by our professional values. My ability to look for the underlying mechanisms behind the events grew even more while working as a nurse at a coronary care unit. At each step, while dealing with my patients, I utilized my explanatory thinking to understand and to make others understand as to *why something unusual happened with the patient*. Sometimes it was as simple as looking for the explanation behind a phlebitis or a fall, the other times, it was as complex as identifying the underlying reasons for an unsuccessful cardiopulmonary resuscitation or an ineffective mechanical ventilation.

It was within cardiology nursing practice that I realized the power of context in shaping up and explaining health outcomes. I came across patients who presented with massive myocardial infarctions but survived, as they presented to the hospital timely, versus those who presented with relatively less serious infarctions but could not survive, due to delayed arrival to the hospital. When explanations were sought through my master's thesis, many contextual realities seemed to play their part such as the time taken to report the symptoms, if the patient went to a general physician (GP) before coming to the hospital, if the GP identified the heart attack symptoms immediately and referred the patient to the hospital, if the ambulance was available at the GP's clinic, if the patient was accompanied by

someone who could help him in reaching the hospital, if there was heavy traffic while the patient was being transported to the hospital, and so on.

My career as a nurse academic enhanced my explanatory thinking further and gave me an opportunity to understand the contextual factors and their effects on outcomes even better. I taught about 100 students in each class, and each of these students performed differently. When I got to analyze their academic performance, I looked for the underlying explanations. There were always some interacting factors that led the student to perform in a certain manner, such as their relationship with parents and siblings, their relationship with peers, the peer pressure, their personality type, their motivations and aspirations, and their intellectual abilities. I used to get amazed at the influence of the context in determining the students' academic outcomes. Very soon, it became an important professional value for me to look at situations within the broader context in which they existed, whether it be student-related or patient-related situations, and to look for the contextual influences that affect the outcomes.

### *Reflexive Account by Author 2*

I grew up in a house dominated by science. My father was and is an avid scientist—having previously worked as a nuclear safety physicist for his career in Scotland. In nuclear safety, the existence of a mind-independent reality is essential. Believing a nuclear power station is safe and ensuring it is via good science are two distinctive claims to knowledge. If calculations are flawed and a radiation leak occurs—whether we believed the reactor to be safe or not is incidental. Further, radioactivity is real—even when we cannot readily perceive this radiation with our senses. This suggests that there is indeed a hidden world beyond our perceptions that has an existence irrespective of whether we believe or recognize this. Reflecting his scientific leanings, our house was overflowing with books on science, engineering, and technology. While this background could have rendered me into a hard positivist—I was also drawn to the social sciences—an appreciation of the cultural and the social—of the messy and the complex. A hard view of science struggled to capture the ambiguity and diversity of social, economic, and cultural aspects of the world. My early career in nursing reinforced to me that as a professional—biological realities were mind independent—tumors existed in patients' bodies irrespective of whether they knew or believed this—but also that social, cultural, and personal aspects were important too. The framing, perceptions, and beliefs individuals had influenced their anxiety, stress, and behaviors. Nursing offered the perfect axiom to draw the biological, social, and cultural together via its holism. Nursing assumed that emancipation was possible, and accordingly that the individual, if given the right support and resources, could successfully transcend difficult circumstances. CR aligned with my professional values and could adequately subsume biological, social, and cultural factors influencing health outcomes—and avoided the

more dogmatic and narrow natural conclusions of the positions of constructivist and positivist alternatives.

### **Role of CR in Shaping Our Research Around Complex HFDMI**

What then are the full implications of this CR meta-theory for a focused program of research? Our current research explores the effectiveness of HFDMI. Heart failure (HF) is the most costly chronic condition affecting high-income countries, affecting around 10% of all people aged over 65 years and up to 40% of people aged >85 years (Blair, Huffman, & Shah, 2013). The syndrome is characterized by the heart's inability to meet the demands of the body. This insufficiency reduces the performance of all the body's systems and results in symptoms of breathlessness, fatigue, fluid retention, and cognitive impairment. The wide prevalence of HF is related to the relative commonality of its causes: in high-income countries, the syndrome results from myocardial infarction (or heart attack) or chronic hypertension (high blood pressure). People with HF can live longer and better lives if they consume appropriate medications at the right dosages and frequency and engage in effective self-care.

HFDMI refer to the interventions provided to people with HF to promote effective self-care. Typically, these interventions are composed of different components. HF self-care interventions, reflecting past research, focus on promoting effective management around medications, alcohol/fluid restriction, weight management, smoking cessation, physical activity, and timely help seeking (Buck et al., 2018). All these strategies reduce the size of demands the heart places on the body, increase the heart's performance, or promote rapid support during the early stages of symptom exacerbation.

HFDMI are very diverse: they vary widely in type and context: from interventions provided in-person in hospitals or clinics, to those provided in the home remotely via telephone, e-mail, Internet, text messages, or apps. Interventions can be provided by a wide range of different health professionals such as nurses or physicians or by multidisciplinary teams. From a CR perspective, the outcomes of these interventions are generated not only by the interventions (such as via the interaction between intervention components) but also by their interaction with the "context" of intervention delivery and the providers and recipients of the interventions (Clark & Thompson, 2010).

Evaluations of HFDMI—including those from randomized trials—have been found to be consistently inconsistent—in both trials and meta-analyses of trials (Clark, Savard, & Thompson, 2009; Clark & Thompson, 2010; Savard, Thompson, & Clark, 2011). Meta-theories such as positivism struggle to subsume such demonstrable inconsistencies—and usually attribute the wide variability in findings to issues around method—notably intervention fidelity, study differences in populations, outcomes, and comparison groups (Clark et al., 2009). Seldom is ontology invoked. This may be because to do so would undermine the ontological basis that has buttressed past research efforts; if interventions cannot be assumed to be

inherently effective, this undermines the careers, guidelines, and practices built of this very basis (Clark & Thompson, 2010). However, the data do appear to suggest that interventions do have markedly different effects across contexts. Merely, carrying out more trials on the same flawed meta-theoretical basis is unlikely to yield markedly different conclusions. Instead, a different focus on a different basis is needed. Via its explanatory focus on complexity, CR is well placed to do this.

Given the presence of complex interactions within and around HFDIMs, CR is a highly appropriate worldview and it provides the most appropriate meta-theoretical underpinning, for exploring this research question.

### **CR's Methodological Eclecticism and Research Around Complex HFDIMs**

What then methodologically does research into HFDIMs grounded in CR look like? As explained earlier, CR can embrace diverse research methods and realizes their value in explaining complex phenomena. We now explore how CR can guide qualitative, quantitative, and mixed-methods research to understand the complex HFDIMs and their effectiveness.

#### *Qualitative Studies Uncover the Mechanisms Underlying Complex Phenomena*

Qualitative studies seek to understand the complex phenomena through the participants' experiences and thus can explicate the perceived *explanations, mechanisms, and the complex relationships* that may not otherwise be identified through quantitative research (McEvoy & Richards, 2006). This is because these phenomena may be unknown unknowns—which go unmeasured due to lack of knowledge or known unknown—factors that are not measured because these are immeasurable.

Qualitative research can be used to understand many aspects of the complexity of HFDIMs: from understanding more about the patients' involvement in HFDIMs to the influence of context. Yet qualitative research has not been widely utilized in complex health intervention trials. A systematic review of complex health interventions revealed that only some of the investigators utilized qualitative components along with the trial, to explore more about the intervention qualitatively. Their findings also indicate that those qualitative studies lacked theoretical underpinning and there were issues with the methods. Also, the qualitative findings were not properly triangulated with the quantitative findings of the trial (Lewin, Glenton, & Oxman, 2009).

When qualitative research is underpinned by the meta-theoretical assumptions of CR, this makes it different from the qualitative research, which is underpinned by constructivism. Based on the CR's notion of stratified ontology and mechanisms that operate in the real domain to produce events that can be experienced in the empirical domain, CR qualitative research aims to explore the mechanisms that make complex interventions effective for the patients. This is different from

the qualitative studies rooted in constructivism that are more interested in describing participants' experiences. Also, underpinned by the CR's assumptions, health care is understood as an open system where many different factors interact to produce patient outcomes. Some of these factors are agency related, that is, individual factors, whereas others are structure-related factors such as culture, organizational norms, resources, setting, and so on. Under these assumptions, the CR qualitative studies seek to understand both agency- and structure-related factors that affect intervention outcomes. Patients', health-care professionals', and family members' experiences and observations help in qualitatively understanding these factors in the open system of health care. This characteristic of CR qualitative studies indicates toward the generative logic, that is, understanding the complex interplay of contextual factors, which is at the heart of CR.

*Hermeneutics.* While CR views reality as being mind independent, this is entirely compatible with recognizing the existence of hermeneutical dimensions of human existence and a constructivist vent (Elder-Vass, 2012). As such, constructivism itself ceases to be the only alternative to positivist meta-theory because constructivism is also compatible with CR meta-theory. CR hermeneutic studies seek to understand the mechanisms deriving phenomena that have been experienced by the participants rather than merely understanding their experiences (Danermark, Ekstrom, Jakobsen, & Karlsson, 2005). It is different from constructivist hermeneutic studies, which emphasize understanding human experiences as a whole. Research into health interventions can benefit from hermeneutics, mainly because of the hermeneutics' focus on *understanding the phenomenon* through people's experiences (Thirsk & Clark, 2017). Therefore, in case of complex HFDIMs, hermeneutics can be extremely useful to understand these interventions and their complex mechanisms of delivery, through the experiences of the patients for whom the intervention is intended, and the experiences of the health professionals who are involved in intervention delivery (Thirsk & Clark, 2017). CR hermeneutic research could, for example, focus on *what can be learnt about the intervention and its mechanisms by utilizing the participants' experience of going through the intervention?*

*Ethnography.* Ethnographic methods involving prolonged engagement in the selected setting can be very useful for the *process evaluation of health interventions* (Morgan-Trimmer & Wood, 2016). Ethnographic data collection methods, notably observations, are powerful tools to explicate the context of intervention delivery, and the causal pathways that make those interventions work—that is, the cultural and contextual factors that affect the effectiveness of interventions and the perceptions of participants about the intervention. For instance, ethnographic work could observe the interactions between health professionals and patients during intervention delivery, family members' participation in intervention delivery, or patient's beliefs that may affect their participation in the intervention.

This would help evaluate interventions holistically, along with the generative effects produced by an interaction of agency-related (patient and family related) and structure-related (health system and health professionals related) factors, rather than measuring intervention effects in isolation. These interactions are important to be explored because these determine participants' motivation and thus whether they continue their participation in the intervention or not. For instance, a cardiac patient who has strong family support and whose family motivates him to participate in the cardiac rehabilitation intervention will be more motivated to attend the rehabilitation than someone who lacks strong family support. Similarly, a patient who has experienced positive and therapeutic communication by health professionals during the health education sessions will be more motivated to attend these sessions, versus someone who has had negative experiences with health professionals.

Indeed, CR ethnographies, underpinned by the meta-theoretical assumptions of CR, are based on the tenet that culture is an integral part of the real world of open systems, which manifests itself in the empirical world in different forms (Barron, 2013). Thus, there is an underlying culture, which may not be seen or heard explicitly; however, it is deriving many observable events in the empirical domain of the world. For instance, in a certain culture, women hold the belief that they should respect their elder-in-laws in any circumstances; since this is a belief, it cannot be observed. However, what is observable are the effects that this cultural belief leads to. A woman from such a culture may even quietly tolerate violence by her in laws, without raising her voice against it. CR ethnography is therefore intended to explore the apparent and the underlying culture. The strategies that critical realist ethnographers can adopt for the exploration of this *underlying culture* are photography; dialogue with participants; observations of participants and their surroundings; analysis of text, observations, and photographs; and reflexivity (Barron, 2013). Through these research strategies, the *underlying cultural mechanisms* can be explored that make HFDMIs effective or ineffective. For instance, one of the underlying mechanisms in the open system of health-care culture is that of dealing with the patients with dignity. This mechanism is brought to the effect with the generative effects of structural factors such as health professionals' behavior with patients, institutional policies, procedures, and practices. A critical realist ethnography can be extremely helpful in exploring if and how a health system's culture promotes patients' dignity.

**Grounded theory.** Grounded theory seeks to generate theory grounded in data (Corbin & Strauss, 1990). Grounded theory can explicate why interventions work when they work, and why they don't when they don't. This ability arises from the ability of grounded theory to explain patterns and variations; this reflects the similar broader explanatory focus of CR. An example of a grounded theory study to understand the barriers for effective diagnosis and management of HF is the one by Fuat, Hungin, and Murphy (2003).

CR grounded theory fulfills emancipatory goals by focusing on understanding the underlying generative mechanisms, in comparison to the traditional constructivist grounded theory, which focuses on mere surface description (Oliver, 2011). For example, many a times, beneath the observables are the human motivations and frustrations, which interact with the structural factors to produce events (Oliver, 2011). The above example of patients' participation in health interventions is appropriate for a CR grounded theory as well. Since attrition rate is high for health interventions, it is important to understand the underlying motivations and frustrations that determine whether the patient continues to participate or discontinues participation in the intervention. In case of HFDMIs, a critical realist grounded theory can be used to understand the process of decision-making utilized by the patients to actively participate in the disease management programs offered to them, or to understand the thinking processes that lead them to leave a particular disease management program in between. This approach will identify what *generative mechanisms* are responsible for proper or underutilization of HF disease management programs.

Reflecting the fallibility that CR always subsumes, CR allows for tentativeness of the findings of grounded theory, assuming that the emerging theory is modifiable (Oliver, 2011). Another feature that CR brings to grounded theory is its openness to embrace several research methods. Therefore, a CR grounded theory can utilize various qualitative and quantitative data collection methods to develop a theory (Oliver, 2011). Rather than the purely inductive approach that is pursued by constructivist grounded theory, a CR grounded theory takes an abductive approach. The researcher begins the research process with some preconceived ideas and has some assumptions about the phenomenon to be explored (Oliver, 2015). This acknowledges that the researcher has a particular lens and encourages the researcher to be upfront about their preconceived assumptions, and to consider them as tentative and subject to change during the research process (Oliver, 2011).

### *Mixed Methods Can Be Extremely Useful in Evaluating Complex Interventions*

Mixed methods provide the best opportunity to triangulate the findings obtained through qualitative and quantitative methods, to be able to reach to the most robust and conclusive evidence (McEvoy & Richards, 2006). This is because mixed methods develop a comprehensive understanding of the phenomenon under investigation; the ability of the mixed methods to explore health conditions through multiple dimensions makes it more effective for complex health intervention research (Chiang-Hanisko, Newman, Dyess, Piyakong, & Liehr, 2016). There are three basic purposes of triangulation: confirmation of findings through various methods, ensuring completeness of findings through the use of multiple methods, and exploring retroductive inferences (McEvoy & Richards, 2006). Therefore, mixed methods can serve to provide confirmed, complete,

and retroductively inferred explanations for the health interventions' effectiveness, which aligns with the intent of CR well.

Adopting a critical realist stance in mixed-methods research offers a sound ontological basis, which supports and justifies the use of diverse methods exploring the same phenomenon, philosophically (Zachariadis, Scott, & Barrett, 2013). The primacy of context and of the underlying mechanisms suggested by CR, and its explanatory nature of ontology, make mixed methods ontologically coherent with the premises of CR. Utilizing the meta-theory of CR, mixed-methods research serve various purposes, which are congruent with the critical realist ontology. For instance, CR assumes a multilayered world (empirical, actual, and real), whereby the exploration of these multiple layers and the events taking place within them requires different methods that can explore both the perceptible events and the unobservable mechanisms. Thus, mixed-methods research provides complementary views over the same phenomenon, painting a complete picture of the phenomenon under study (Zachariadis et al., 2013). Also, following the retroductive approach of CR, mixed methods can be used to draw inferences using one research method, and then developing further research questions to explain those inferences, which can then be answered through other relevant research methods (Zachariadis et al., 2013).

In relation to the HFDIMs, one of the many possible examples of a mixed-methods study could be: first, identifying through a quantitative approach, the components of the HFDIMs that work the best in a particular setting and context, and later exploring qualitatively *if and why* the participants found those interventions to be effective and inclusive. The triangulated findings of this mixed-method study will provide a complete understanding of the effectiveness of those interventions. These triangulated findings are important, so that effectiveness of interventions can be linked with the contextual factors that made those interventions effective. Without this exploration, the intervention may yield different outcomes when applied in different contexts, since we would not have any information about which characteristics of health professionals, health setting, and resources made that intervention work for the patients.

**Quantitative component of mixed-method research.** By virtue of its meta-theoretical assumptions, CR does not underpin randomized controlled trials (RCTs), which are based on successionism and linear relationship between the intervention and the outcomes (Marchal et al., 2013). It has been argued that the traditional RCTs can predict cause and effect relationships in closed systems, but they miss onto the most important contextual factors that intervene in an open system-like health care. Alternatively, studies underpinned by CR explore, not only the effects of the intervention but also the organizational structure and culture, resources, and the actions of the people involved, to understand how these factors affect intervention effects (Porter & O'Halloran, 2012). Quantitative components of mixed-methods studies, which are underpinned by CR, intend to find

associations between the participants' contextual factors, that is, their socioeconomic and educational background, their level of understanding, their support systems, and their participation in the complex health interventions (McEvoy & Richards, 2006).

An example of such a study would be the one that identifies the association of participants' socioeconomic and educational status, their clinical condition (blood pressure and heart), and their level of family cohesion, with the participants' involvement in the intervention and with the intervention outcomes. All these data refer to the participants' *context* and can help in understanding participants' level of involvement in a particular intervention. Thus, this cross-sectional study is guided by CR as the data, obtained through this study, explain why a certain intervention would work for some people and not for the others.

### Critical Realist Reviews

CR can also underpin studies using secondary data. A CR review focuses on reviewing literature related to complex social interventions, processes, and practices. Looking through the critical realist lens, such a review seeks to unpack the complex social phenomena in terms of their components, the interactions between components and with the context, and the mechanisms involved in determining outcomes. This approach covers the complexity of social phenomena in complete breadth and depth (Edgley, Stickley, Timmons, & Meal, 2016). A CR review approach works best for evaluating health service interventions such as HFDIMs, which work within complex social systems. These interventions are usually composed of several interacting components, and these are greatly affected by contextual factors. Thus, a critical realist review of these interventions is an attempt to unpack: *what works the best for whom, where, how, and why?* One of the examples of a critical realist review is our upcoming synthesis, which will utilize network meta-analysis, a sophisticated approach, to identify the key components of interventions, the interactions between those components and with the context of intervention delivery.

### Conclusion

In conclusion, health research needs to be adequately grounded in meta-theoretical assumptions. Meta-theories are better articulated and reflected in research methods when these are selected by the researchers, considering their historicity, beliefs, and values. Our research around HFDIMs is grounded in CR, which is characterized by seeking explanations through generative logic and multifactorial causation. The beauty of CR is in its methodological eclecticism, drawing from quantitative, qualitative, and mixed methods, in an attempt to explain why things happen the way they do. The article illustrates CR's openness to the various research methods using examples from the research around complex HFDIMs, so as to explore which *HFDIMs work the best for whom, where, how, and why?*

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### **Chapter 3: Literature Review- Intersectionality and Heart Failure Care**

#### **Manuscript 2**

**Title:** Intersectionality in Heart Failure Self-care: Ignorance Is Not an Option

**List of Authors:** Saleema Allana, David Thompson, Chantal Ski, Alex Clark

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## Intersectionality in Heart Failure Self-care Ignorance Is Not an Option

Saleema Allana, PhD; David R. Thompson, PhD; Chantal F. Ski, PhD; Alexander M. Clark, PhD

Heart failure (HF) self-care efforts are shared between patients and lay caregivers but are often badly done yet are also poorly understood by patients, caregivers, and their health professionals alike.<sup>1–4</sup> Yet, the contributions of each remain vital to effective HF self-care.

Reasons for poor HF self-care practices are numerous and complex.<sup>1</sup> Effective HF self-care is difficult—it requires a wide range of sophisticated management activities, from medication management and help-seeking to the promotion of good mental well-being.<sup>4,5</sup> Caregiving during HF not only is limited to visible care activities but also includes cognitive and interpersonal skills associated with perception, monitoring, assessment, and communication.<sup>2</sup>

During the last decade, gender and sex differences in aspects of heart disease have been increasingly recognized in a myriad of different ways, for example, via dedicated guidelines, specialist conferences, and thousands of dedicated research studies. This increase in activity and awareness around sex and gender is welcome, but research is now urgently needed to go deeper and further—to explore in earnest how sex and gender interact with other salient patient and caregiver characteristics. In short, research into HF self-care needs to embrace “intersectionality.”<sup>6</sup>

### What Is Intersectionality?

Intersectionality is a paradigm that acknowledges that patient outcomes are rarely shaped by 1 single factor.<sup>7</sup> Growing out of feminism for the past 20 years, intersectionality challenges how researchers and practitioners understand and research psychological, social, and biological realms.<sup>8</sup> Intersectionality challenges us to think beyond the unitary approaches that have thus far dominated heart disease research, whereby categories or characteristics, such as race, gender, class, and so forth, are examined singularly.<sup>8</sup> Instead, intersectional research studies the nature and/or effects of a combination of salient characteristics.<sup>7</sup> Accordingly, a person is not only conceived as being characterized by his or her sex, age, race, or socioeconomic or immigration status but

as a combination of various factors—such as middle-class male older adult of African origin who is an immigrant to Canada. Whether and how these factors interact to influence care-related experiences, behaviors, and outcomes moves to become a central facet of intersectional inquiry. Yet, to date, research into HF self-care using or reflecting intersectionality has been limited in quality and volume. Current studies focus exclusively on single-factor analyses. For example, a recent study exploring HF caregiving around race<sup>9</sup> incorporated no other social factors in the analysis.

Although no study authors to date have adequately examined HF self-care from an intersectional perspective, the potential contributions of intersectional approaches were illustrated well by a Canadian study of caregiving from the perspective of intersectionality among older adults with multiple chronic conditions.<sup>10</sup> This study identified that the caregivers' gender, age, education, employment status, ethnicity, and degree of social connectedness all affected their caregiving role in multiple ways. In addition, the participants' caregiving role had a major influence over wider aspects of their life, including work, health, and family. This has important insights for HF researchers as the similar intersecting characteristics may affect caregiving in HF as well, and therefore, these need to be explored in the context of HF.

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## Using Intersectionality to Explore Heart Failure Self-care

Research into HF self-care needs intersectional approaches because, although this care has strong biological benefits, this care is also fundamentally socially grounded—that is, it occurs in and through a myriad of other social roles. As such, particularly with growing societal plurality around gender identities and solid evidence that social factors, such as ethnicity and class, individually contribute to cardiovascular incidence and prevalence,<sup>11</sup> knowledge is needed urgently as to how such factors interact in HF self-care.

Intersectional approaches will require researchers to explore current trends closely in more discrete intersectional populations. For example, a recent study conveyed well that caregiving is both complex and demanding for caregivers in terms of physical, mental, and emotional burden.<sup>12</sup> How, for example, might these challenges differ depending on the sex of the caregiver and their immigration or income status? Furthermore, this study identified that caregiving caused considerable social role conflict as caregivers' roles changed frequently in response to the symptoms and needs of the patient.<sup>12</sup> How would this conflict be affected by the gender and ethnicity of the patient and caregiver(s) involved? The caregivers themselves retained an enduring evolving sense of personal identity, which also reduced their personal resilience and led to them compromising their own health. Rather than sharing their challenges, the caregivers did not express their difficulties openly or frequently.<sup>12</sup> Yet, if the caregivers were affluent men, would these patterns be any different? Intersectionality entices us to ask nuanced questions of existing general trends—and provides both a theoretical justification and means for doing so. In contrast to the bulk of this existing research, future intersectional approaches should incorporate adequate theory to develop truly intersectional study designs.

## Priorities for Future Topics Using Intersectional Approaches

What should future intersectional research into HF self-care look like in terms of design? In terms of methods, intersectionality-based research can use qualitative or quantitative data but should also embrace both empirical and theoretical studies.<sup>8</sup> Although some researchers argue that qualitative research suits the nature of intersectionality research better, many quantitative instruments are also available to explore intersectionality.<sup>13</sup> These include analysis of variance, hierarchical analysis, cross-tabulation, logistic regression, and multiple linear regression.<sup>13</sup> Through these sophisticated statistical analyses, confounding characteristics or variables can be controlled for and the interactions between various intersectional characteristics can be observed. Qualitative and mixed-method designs have a huge potential in intersectionality research because these methods explore interactions of social roles, expectations, needs, and challenges associated with intersectionality in various circumstances.<sup>14</sup> Existing approaches to HF self-care in which intersectional approaches could add value include research into patients and caregivers:

- Experiences of self-care<sup>12,15,16</sup>
- Unmet needs<sup>17</sup>
- Characteristics of caregivers of patients with HF<sup>18</sup>
- Effects and harms from caregiving<sup>19,20</sup>
- Emotional well-being, stress, burnout, and anxiety<sup>15,21</sup>
- Knowledge, confidence, and skills around HF self-care<sup>15</sup>
- Nonadherence to recommended self-care practices<sup>15</sup>
- Social isolation, familial support, and health professional support<sup>15</sup>
- Differential effects from self-care interventions<sup>22</sup>

This intersectional research should incorporate sex, gender, class, ethnicity, and immigration status into sampling.<sup>6</sup>

In conclusion, research using intersectional perspectives is urgently needed to strengthen the quality

and relevancy of research into HF self-care. This can deepen and broaden insights into key populations and provide a more nuanced evidence base to inform healthcare practices and policy and to improve HF self-care and outcomes in both patients and their caregivers.

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### **Manuscript 3**

**Title:** Intersectionality and Heart Failure: What clinicians and researchers should know and do

**List of Authors:** Saleema Allana, Chantal Ski, David Thompson, Alex Clark

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## Intersectionality and heart failure: what clinicians and researchers should know and do

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### Purpose of review

To review the application of intersectionality to heart failure. Intersectionality refers to the complex ways in which disenfranchisement and privilege intersect to reproduce and influence health and social outcomes.

### Recent findings

Intersectionality challenges approaches that focus on a single or small number of socio-demographic characteristics, such as sex or age. Instead, approaches should take account of the nature and effects of a full range of socio-demographic factors linked to privilege, including: race and ethnicity, social class, income, age, gender identity, disability, geography, and immigration status. Although credible and well established across many fields – there is limited recognition of the effects of intersectionality in research into heart disease, including heart failure. This deficiency is important because heart failure remains a common and burdensome syndrome that requires complex pharmacological and nonpharmacological care and collaboration between health professionals, patients and caregivers during and at the end-of-life.

### Summary

Approaches to heart failure clinical care should recognize more fully the nature and impact of patients' intersectionality- and how multiple factors interact and compound to influence patients and their caregivers' behaviours and health outcomes. Future research should explicate the ways in which multiple factors interact to influence health outcomes.

### Keywords

chronic heart failure, discrimination, heart failure, intersectional, marginalization, social theory

## INTRODUCTION

Intersectionality is about the complex ways in which disenfranchisement and privilege come together to reproduce and exert influence [1,2]. Intersectional approaches are credible and increasingly common across political and social movements and disciplines [3–6], including in health [7–10] and its research methods [11]. As we will show in this review, although intersectionality can inform clinical practice [12\*] and research [13], it has yet to become prominent or used around either heart failure [14\*\*] or heart disease [11]. This paper is a primer to what intersectionality is, why it is important, and the implications for clinical practice and research into heart failure.

## WHAT IS INTERSECTIONALITY?

Health outcomes in the United States over the life course for black African American women of *high*-socioeconomic status are as adverse as those for *low*-socioeconomic white women: this is intersectionality

exemplified [12\*]. Intersectionality rejects the notion that humans fall into simple single socio-demographic categories [11]. Instead, intersectionality posits that aspects of race and ethnicity, social class, income, age, gender identity, disability, geography, and immigration status intersect in complex ways to perpetuate privilege and disenfranchisement [1].

It is neither controversial nor new to state that humans fall into multiple social categories [11]. We each concur with this notion – resisting being reduced to just our age or sex. Instead, we might view ourselves, for example, as a partially sighted, middle-aged, middle-class, Caucasian, European,

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### KEY POINTS

- Intersectionality is a credible and increasingly common approach to understanding how privilege influences aspects of life – including health and social outcomes.
- Intersectional approaches explore how aspects of sex, race and ethnicity, social class, income, age, gender identity, disability, geography, and immigration status interact to influence life opportunities, quality, and expectancy.
- Intersectionality challenges conventional approaches in practice and research which place excessive emphasis on the influence of single or small number of socio-demographic characteristics, notably: sex or age.
- There is limited recognition of the effects of intersectionality in research into heart disease, including heart failure.
- Intersectional approaches offer a promising means for improving and understanding heart failure outcomes and self-care and for potentially reducing inequities in outcomes.

Canadian, Scottish or British woman. We may even go further to associate with being cis (i.e. having the gender that was ascribed to us at birth) or gender fluid – choosing to dissociate oneself from any specific gender identity. Yet, despite these growing multiplicities, research into epidemiology, cardiology and public health mostly retain simplistic approaches to a small number of simple social and demographic factors, which are themselves simply analysed - this disregards the intersection of these single factors with the other characteristics of these patients, and the effect of this intersectionality on health [11,15<sup>22</sup>,16].

### THE GROWTH OF INTERSECTIONAL APPROACHES

Over the last two decades, the field of intersectionality has grown rapidly to provide a credible and timely challenge to how researchers and practitioners approach and research biological, social and psychological realms [15<sup>22</sup>,17,18].

There are compelling empirical and ethical justifications for intersectional approaches to heart disease [11,14<sup>22</sup>]. First, even in the absence of intersectional approaches, it is well established that personal, social and demographic factors interact and compound to generate stepwise increases in levels of adversity in heart health outcomes over the life course [11,16]. Intersectional approaches can document and understand these interactions better,

particularly around established but often neglected factors, such as race [12<sup>2</sup>,15<sup>22</sup>], disability [19], and emerging social factors entwined with health and social wellbeing, such as geography and gender-identity [19,20].

Given the centrality of health behaviours and healthcare usage to cardiovascular risk over the life course, to both assess and address primary and secondary prevention and disease management, intersectional approaches have considerable potential to capture the complexities of privilege, especially in how different factors interact to influence cardiovascular-related behaviours and outcomes [11,16]. This complements but also critiques increasingly widespread movements to promote ‘women’s heart health’ or ‘men’s health’ – which risk downplaying or dismissing the diversity and complexity associated with intersectionality by dint of their binary and singular focus [1]. This lack of intersectionality neglects, for example, the negative compounding effects of other factors on women, such as race, disability, or low socioeconomic status [11,15<sup>22</sup>]. The encouraging developments over the past two decades in increasing the understanding and profile of heart disease in women must now be eclipsed by concerted attempts to incorporate intersectional approaches with such gender-aware approaches [1]. Similarly, heart failure is an area of care and research much in need of intersectional approaches.

### HEART FAILURE NEEDS INTERSECTIONAL APPROACHES

Effective investigation, diagnosis, prescribing, and support for self-care are all central to effective heart failure management [21]. Given most people with heart failure are located at home, effective clinician-patient collaboration, mutual communication, and support for heart failure self-care are powerful tools to improve long-term quality of life, reduce personal and economic burdens, and improve hospital readmission rates and mortality [22–25].

Heart failure self-care is multifaceted, requires daily and even hourly attention, and extends across aspects of pharmacological, behavioural and lifestyle management [22] (Table 1). Yet, systematic reviews have shown that months and even years after diagnosis, heart failure patients and caregivers lack a basic knowledge of the nature of heart failure, and how it connects to self-care activities [26,27].

Moreover, heart failure self-care has been approached and researched predominantly as a rational cognitive endeavour. Thus, research has focused on experience, knowledge, decision-making ability, cognitive impairment, symptom perception, and self-efficacy [28–30]. This ignores evidence that

**Table 1.** Key domains of heart failure self-care management [22]

Domain	Components
Pharmacological management	
Medication-consumption	Adherence/concordance with prescribed regimen
Behaviour and Lifestyle	
Symptom Monitoring	Do daily weigh monitoring
Dietary change	Regulate and reduce sodium intake in diet
Fluid restriction	Regular fluid intake (usually below 2 l/day)
Alcohol restriction	Regulate alcohol intake (e.g. 1–2 glass wine/day)
Weight loss	Avoid being overweight
Physical activity	Engage in moderate regular physical activity
Smoking cessation	Stop tobacco smoking

heart failure self-care is strongly influenced by a wide-range of psychosocial and contextual factors [31,32] linked to intersectionality [18]. These include: personal and social values [33], social, occupational and financial context [27], rural setting [34], cultural beliefs [33], social norms [26,35], spiritual and cultural preferences and practices [36], and social support [31].

Further still, it is clear that daily heart failure self-care is more of a collaborative rather than an individual endeavour – it involves patients and their spouses and family in daily management [27,37–38]. In the context of caregiving, this entails that families (and other caregivers) can support a vast array of immensely complex activities, including: those linked to effective disease management (extending across nutrition, physical activity, medication and device management, smoking cessation, and symptom assessment and monitoring), promoting timely access to and navigation of the health system, supporting daily living and psychosocial well-being, and assisting with end-of-life decisions [37]. As such, an intersectional lens focused on heart failure acknowledging individual variation must extend to include family and other informal caregivers.

Given the need for intersectional approaches to heart failure, how much has intersectionality featured in current approaches to practice and research in heart failure?

### CURRENT EVIDENCE ON INTERSECTIONALITY IN HEART DISEASE

Although intersectionality was first described well over a decade ago [17,18], and it has implications for

health and gender, research methodology and populations [13,39–41], scant acknowledgement of intersectionality has appeared in the heart disease literature, despite exhortations to use intersectional approaches, for example, in heart failure self-care [14<sup>22</sup>]. The literature does refer to the term ‘intersection’, for example, heart failure at the intersection of heart failure and palliative care [37]. However, despite the widespread and growing knowledge of the nature and importance of intersectionality, there is a wanton lack of commentary and research on intersectionality around heart failure.

This is surprising when intersectionality can aid analysis of power dynamics driving health disparities and further understanding of risk heterogeneity in epidemiology, including for cardiovascular disease [11]. For example, though it is well recognised that cardiovascular disease is the leading cause of death globally, and there are differences in its distribution and risk by geography, socioeconomic status, race or ethnicity, and sex and gender, such factors have often been studied individually, with less attention having been given to within-group differences in terms of aetiology, onset, trajectory, health-seeking, and outcomes across differentially situated women and men [9]. An intersectionality lens systematically examines various factors affecting cardiovascular disease simultaneously, bringing attention to the synergistic effects of heterogeneous risk factors and experiences [11].

If we use heart failure as an example, we may find, for example, that Métis indigenous populations in Canada and Australia experience a disproportionate and growing burden of the syndrome compared with nonindigenous Canadians and Australians [42,43]. This results from a distinctive combination of factors such as lower average socioeconomic status, higher levels of alcohol and drug consumption, wider prevalence of poor mental health, lower levels of physical activity, and greater barriers to accessing or receiving health services [42,43].

Chronic diseases such as heart failure and their inequalities amongst older adults pose a significant public health challenge. The prevention and treatment of heart failure will benefit from insight into which population groups show greatest risk. A recent study from Sweden [11] illustrates this by reporting the analysis of disparities in a common set of biomarkers at the population level. This study adopted an intersectionality perspective and found granular intersectional disparities, which varied by biomarker, with total cholesterol and HbA1c showing the greatest intersectional variation. These disparities were additive rather than multiplicative. Whilst the majority of variation in biomarkers

was at the individual rather than intersectional level, the average differences were potentially associated with important clinical outcomes. This intersectional perspective helped to shed light on how socio-demographic factors combine to result in differential risk for disease or potential for healthy ageing [44].

Another recent study from Spain [45] comprehensively analyzed from an intersectional perspective social inequalities in cardiovascular (including heart failure) mortality by considering the joint influence of age, sex and education. The greatest inequalities were observed in ischemic heart disease and heart failure in younger women. Cardiovascular mortality was inversely associated with educational level. This inequality mostly affects premature mortality due to cardiac causes, especially among women [45].

Given the lack of current research to inform intersectional approaches to heart failure, we make the following recommendations for practice and research in this important area of healthcare.

### RECOMMENDATIONS FOR CLINICAL PRACTICE

Awareness of the concept of intersectionality among clinicians and its incorporation into clinical guidelines remains disappointingly low [15<sup>11</sup>]. Yet, intersectionality challenges clinicians involved in heart failure care in profound and deep ways [14<sup>12</sup>]. How, for example, do facets such as race, gender, sexuality, and class interact to influence individual patients' and caregivers' circumstances, needs, and perspectives [12<sup>13</sup>]? How can practitioners develop and maintain approaches that incorporate intersectionality in their work and interventions with patients and their caregivers [12<sup>13</sup>,14<sup>14</sup>]?

Intersectionality demands practitioners employ sophisticated approaches to patient care that go beyond a simple cultural awareness. This is captured well by Wilson and colleagues' challenge to practitioners to add a deep intersectional dimension to their work [12<sup>13</sup>]: *'...to consider the multidimensional axes of a patient's identity ...to understand a patient's background, perspectives, areas of vulnerability, and needs more fully...to supplement cultural competence and humility. It draws attention to structural and institutional forces that lead to the patient's experience of marginalization on account of these intersecting identities. In this way, intersectionality goes well beyond cultural competence and humility.'*

The implications of an intersectional lens for clinical practice are substantial: the approaches compel clinicians to confront their own, often deeply held, biases [12<sup>13</sup>]. Clinicians should question

their assumptions and explore their interactions with patients for evidence of the presence and influence of intersectionality [12<sup>13</sup>], moving away from approaches to care based on risk assessment confined to single features such as the patient's sex [15<sup>11</sup>].

Individualized care plans to promote effective heart failure self-care and end-of-life support should be sensitive and respond to intersectionality. For the stages of heart failure care, intersectionality steers clinicians to think and act in ways that challenge the more simplified patient descriptors that proliferate in most textbooks, trials, and guidelines. To understand, for example, how risk factors for poor heart failure self-care (and associated co-morbidities) may be influenced by intersectional risks. To recognize the compounding negative interactions of more neglected risk factors (notably race) with other well-recognized factors (notably sex) [11,15<sup>11</sup>].

This is especially important because of the wealth of evidence suggesting that for heart failure self-care and end-of-life care to be effective, both patients and their informal caregivers (usually spouses) need to be involved and work collaboratively with the clinician [27,37]. As such, consultations should be tailored to address the combination of intersectional factors that also potentially influence family caregivers' willingness and capacity to support patients.

Although demanding and theoretically complex, the notion of understanding patients' and caregivers' *different sources of disadvantage* [12<sup>13</sup>] will readily chime with clinicians across all health disciplines who are adept at individualizing and adapting their diagnoses of and approaches to different patients. For practitioners, incorporating intersectionality is then more a natural extension of an existing skill [12<sup>13</sup>].

At the health services level – in chronic care and disease management program design – it is vital to embed this intersectional approach in protocols for program design and program content. Where possible, health education materials for patients and caregivers should acknowledge the presence and influence of intersectional forces on patients' and caregivers' daily lives, and attempt to provide most intensive support to patient groups who suffer the most severe intersectional disadvantages. Where possible, program evaluation data should be recorded to measure and ascertain the effects of these disadvantages in the care context.

Echoing this move to complexity, future guidelines for clinical research need to better recognize the presence and influence which intersectional factors have on diagnosis, treatment and disease management of heart failure. Although guidelines

which acknowledge the distinctive influence of race [15<sup>■</sup>] or patient sex [46] are important, ironically, these risk ignoring the strong and persuasive evidence that it is intersectional forces that exert most influence on health and health outcomes over lifetimes [12<sup>■</sup>,16].

## RECOMMENDATIONS FOR RESEARCH

The introduction of intersectional approaches into heart failure patient care is hampered by the comparative lack of research featuring or exploring intersectionality in both heart disease and heart failure. Progress has been made in raising clinician and public awareness of the influence of being female on risk of coronary heart disease, self-care, and use of cardiac health services [47], or the influence of race [15<sup>■</sup>]. Although commendable, in intersectional terms, this recognition of such single factors, is inadequate and even unhelpful.

There is a growing awareness of the limitations of approaches to epidemiology and clinical trials which fall prey to the pitfalls of social categorization in ignoring the clinical heterogeneity of patients and populations for research feasibility [11,16]. Such approaches have been criticized extensively in the emerging field of *discriminatory accuracy* – which calls for intersectional approaches to investigate the ‘interaction of multiple axes of social differentiation and, thereby, help us to understand individual heterogeneity’ [16]. This movement draws renewed attention to the long-held critique that vast swathes of research into more general patterns in populations do not acknowledge individual heterogeneity and the resultant complexity required of person-centred care [16]. This critique is particularly apt in heart failure due to the multiple complex determinants of health across social, psychological and biological realms, associated with heightened risks for cardiovascular disease and reduced capacity to use health services and engage in effective self-care [14<sup>■</sup>].

Research studies should be prioritized to identify the nature of intersectional risks associated with adverse care outcomes around healthcare, self-care and end-of-life care. Approaches to study conception and design must move beyond, at minimum, recognizing the influence of being female or race [15<sup>■</sup>] on patients’ care, experiences and outcomes. Instead, protocols are needed which incorporate analyses based on the presence and interaction of multiple variables including race and ethnicity, social class, income, age, gender identity, geography, and immigration status [1].

The benefits and justification of wider incorporation of intersectionality extends beyond social justice and theory [11]. Notably, intersectionality

stands to improve the discriminatory or prognostic accuracy of diagnostic tools, biological or other markers for heart failure– which will strengthen predictive validity of current and future technologies [11]. In epidemiology, moves to measure the larger numbers of intersectional social risk factors will markedly improve the transferability of results from populations to individuals [16]. In qualitative research, intersectional approaches to study conception and recruitment will better reflect the true intersectional complexities of patients and their caregivers.

## CONCLUSION

It is timely and ethically important to recognize the presence and influence of intersectionality in heart failure practice and research. Intersectionality offers promising ways to improve care outcomes, reduce inequities, and improve research into the complexities of heart failure self-care and outcomes.

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There are no conflicts of interest.

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- of special interest
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## **Manuscript 4**

**Title:** Bringing Intersectionality to Cardiovascular Health Research in Canada

**List of Authors:** Saleema Allana, Chantal Ski, David Thompson, Alex Clark

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## Editorial

## Bringing Intersectionality to Cardiovascular Health Research in Canada

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Cardiovascular disease (CVD) affects various subgroups of the population; some are disproportionately affected more than others.<sup>1,2</sup> Besides genetic and clinical factors, an important set of social factors intersect to shape our cardiovascular health outcomes. Disparities in CVD are numerous and wide-ranging, having evolved mainly from inequalities in society. Some populations carry a higher risk of CVDs, a higher prevalence of CVDs, and worse outcomes with CVDs.

Race, immigration status, sex, gender, and sexual orientation are some examples of the social factors that can determine not only our risk of heart disease but also our responses to therapies and our access to services.<sup>3–6</sup> These factors compound existing health inequities, but they are less isolated factors than they are intersecting factors. Consequently, an understanding of how this *intersectionality* influences cardiovascular health outcomes is now key.

Therefore, this paper calls for bringing an intersectionality lens to cardiovascular health research, which eventually would enable us to practice intersectionality-based cardiovascular medicine.

### What Is Intersectionality?

Intersectionality acknowledges the various identities that each of us carries, and how these identities intersect to bring about either oppression or privilege.<sup>7,8</sup> As individuals, we are known socially by our identities, such as age, gender, sexual orientation, race/ethnicity, religion, social class, immigration status, and place of residence (rural/urban). Each of these identities can put us in a position of relative power or

disadvantage; however, practically, each of these identities can also interact with other factors, thus reinforcing and compounding privilege, discrimination, and inequities.<sup>8</sup> As examples of intersectionality, consider elderly rural women, an immigrant of South Asian descent, or a Black lesbian. These intersecting identities not only define us socially, but also have a lot to do with our health behaviours, and our physiological and psychosocial health, all of which contribute to our risk of acquiring and the outcomes of various diseases. CVD is no exception. About 90% of the risk of myocardial infarction comes from the 9 risk factors that are closely linked to our health behaviours,<sup>9</sup> and a wide range of factors influence health services usage.<sup>10</sup> For instance, older women with heart failure living in rural areas are less likely to follow self-care recommendations<sup>11</sup>; South-Asian immigrants have both an increased prevalence and an increased death rate from coronary artery disease<sup>12</sup>; and Black lesbian women tend to have a higher prevalence of cardiometabolic risk factors.<sup>13</sup>

Despite the fact that such intersecting factors can influence the incidence and treatment of CVD, intersectionality largely has been ignored in cardiovascular health research in Canada and globally, to date. Some studies have examined the intersection of race/ethnicity and sexual orientation and the contributions it makes toward developing the risk of CVD.<sup>13,14</sup> Some studies have looked at the intersection of income and work status with the place of residence (rural/urban) and how it shapes self-care in heart failure.<sup>15,16</sup> However, the vast majority of studies of cardiovascular health focus on singular factors and their impact on patient outcomes, leaving intersectionality and its effects unexplored and unacknowledged.

### Why Is Intersectionality Important for Exploration of the Cardiovascular Health of Canadians?

The neglect of intersectionality in Canadian CVD research is notable because the Canadian population is immensely diverse—with unusually high cultural and gender diversity,

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along with significant rurality and indigeneity.<sup>17</sup> Canada has accordingly come to be known as a land of immigrants and multiculturalism. Each year, Canada welcomes around 300,000 new immigrants of varied ethnic backgrounds. These individuals come from South Asia, South East Asia, the Middle East, the US, Africa, and Europe; they speak hundreds of different languages and bring with them their own unique cultures.<sup>18</sup> In terms of gender diversity, about 900,000 Canadians described themselves as either lesbian, gay, or bisexual in the Canadian Community Health Survey (2015-2018), which is about 3.3% of the total Canadian population aged 15 years or more.<sup>19</sup> Moreover, the Canadian population is a mix of people living in rural and urban areas, and of various social classes. Per 2019 statistics, about 19% of Canadians live in rural remote areas, where access to healthcare is a major issue.<sup>20</sup> Additionally, about 4% of Canadians identify themselves as Aboriginal or indigenous.<sup>21</sup> This unusually high diversity within the Canadian population is also reflected among the Canadian cardiovascular patient populations. Therefore, it is extremely important to explore the effects of intersectionality on cardiovascular care and outcomes, especially in the Canadian context.

### Why Is Intersectionality Important for Cardiovascular Health Research?

Cardiovascular health research is broad; it explores the prevalence and outcomes of CVDs, determines the efficacy of various treatment modalities, and examines self-care and disease management for chronic cardiac conditions, and the lived experiences of cardiovascular patients and caregivers. For each of these outcomes, several intersections of identities could be explored, which would result in generation of specific findings about the treatment/intervention or disease management program that is best suited to improve outcomes among specific populations of cardiovascular patients (see Table 1 for some examples of intersectionality-based cardiovascular research questions, outcome measures, and the intersections of identities explored).

Intersectionality applies everywhere. As much as it is imperative to account for intersectionality while

predicting risks and outcomes of CVD and determining efficacy of treatments for specific patient groups, it is equally important to study health behaviours, self-care abilities, and lived experiences through an intersectionality lens.

Based on the type of outcome to be explored, the research methods can vary. Intersectionality embraces a broad range of research methods. For instance, epidemiologic studies could be conducted to determine risks, prevalence, and outcomes of CVD among various subgroups of the population that have intersecting factors affecting their cardiovascular health. Intersectionality-based interventional research can be carried out as a means to delineate the effectiveness of treatment modalities for various subgroups of cardiovascular patients. Mixed-methods research can be performed to explore self-care abilities and disease management among cardiac patients with intersecting identities. Lastly, intersectionality-based qualitative research could be undertaken to understand the experiences or perceptions of various subgroups of cardiac patients and their caregivers relating to living with and managing their condition. Important to note is that there is a stark need to move beyond what can be inferred from traditional cardiovascular research methods and more toward implementation of informative and inclusive interventions designed to address patient needs.

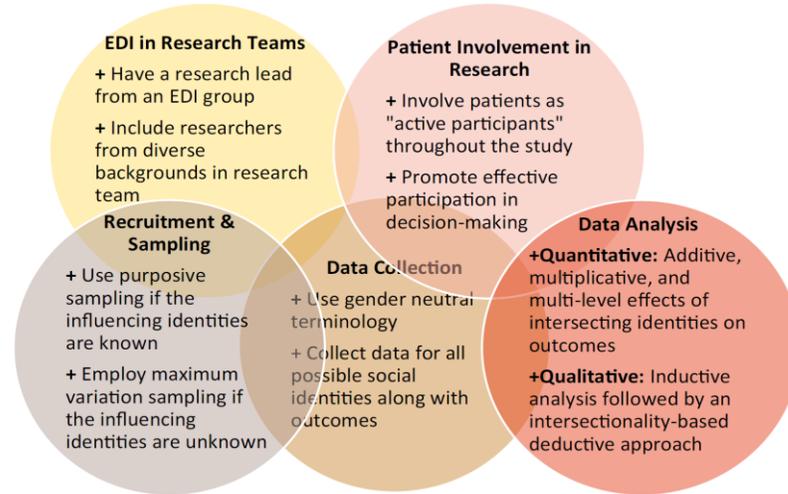
### In What Ways Can Intersectionality Be Applied to Cardiovascular Health Research?

Intersectionality can be applied to cardiovascular health research in many different ways and at various levels. Intersectionality can be fully integrated through a research project, which means recognizing that the research is underpinned by the intersectionality theory, and subsequently weaving in intersectionality through each stage of the research. Alternatively, intersectionality could be applied at some or all of the stages of the research process (please see Fig. 1 for integration of intersectionality at various stages of the research process).

Even if the research is not entirely grounded in intersectionality theory, the influence of patients' intersecting identities on a specific cardiovascular health outcome can be

**Table 1. Examples of intersectionality-based cardiovascular research questions with intersections of identities explored and outcome measures**

Subject #	Examples of intersectionality-based cardiovascular research questions	Intersections of identities explored	Outcome measures
1	How effective is aspirin in preventing myocardial infarction in Black lesbian women?	Ethnicity, gender, sex	Effectiveness of treatment modality (aspirin)
2	How accessible, relevant, and effective are heart failure disease management programs for elderly rural women in Canada?	Rurality, age, place of residence	Accessibility, relevance, and effectiveness of heart failure disease management programs
3	What are the risk factors associated with coronary artery disease among Black transgender men in urban settings?	Race/ethnicity, gender, place of residence	Risk factors of coronary artery disease
4	What are the clinical outcomes after angioplasty among middle-class Caucasian urban-dwelling women?	Social class, race, place of residence, gender	Clinical outcomes after angioplasty
5	What is the compliance with statin prescriptions among retired older men with cardiovascular disease who do not have employer-provided insurance coverage?	Employment status, age, gender, insurance coverage	Compliance with treatment modality (statins)
6	What is the prevalence of ST-elevation myocardial infarction among labor-class Latino men?	Social class, race, gender	Prevalence of ST-elevation myocardial infarction
7	How frequently are immigrant women of South Asian descent referred to a cardiac rehabilitation program?	Ethnicity, sex, immigration status	Access to cardiac rehabilitation services
8	What are the lived experiences of interactions with cardiologists in bisexual Hispanic men?	Sexual orientation, ethnicity, gender	Lived experiences of interactions with cardiologists



**Figure 1.** Steps for integrating intersectionality into cardiovascular health research. EDI, Equity, Diversity, and Inclusion.

examined (see Table 1 for some examples of intersectionality-based cardiovascular health research questions).

Research priorities are often significantly affected by funding agencies' mandates and government-based incentives.<sup>22</sup> This effect holds true for intersectionality-based research in CVD as well, with the impact that the potential for intersectional research in cardiology is greater when funding agencies call for including diverse patients and research team members, and when there are dedicated incentives for researchers who are promoting intersectionality-based research.<sup>23</sup>

### **Equity, Diversity, and Inclusion Representation in the Composition and Leadership of Research Teams**

Increasing the diversity of a research team is one way to promote intersectional research in cardiovascular health and disease.<sup>23</sup> Having a lead researcher who is from an Equity, Diversity, and Inclusion group, as well as having research team members from diverse backgrounds, promotes rigorous research in the area of health disparities, as each team member brings to the work a unique and personalized understanding of health inequities.

### **Patient and Public Involvement in Research**

Intersectionality-based research can benefit greatly from patient and public involvement.<sup>24</sup> Patient engagement, especially of those with relevant intersecting identities, right from the beginning stage of research question formulation and research planning, is essential to ensure that we address the research questions that are relevant to these patients and their communities.<sup>24</sup>

Cardiovascular health research needs patient-partnered interventions, involving patients as active participants so that intersecting identities can be explored through promotion

of participation in decision-making, including input into choices and preferences about their care, and opportunities to explore and understand the impacts of various intersecting identities on outcomes.<sup>24</sup> Only through targeted interventions that proactively involve participants and aim to increase awareness of intersectionality and its impacts can we start to deliver appropriate, acceptable, and equitable care to all.

### **Recruitment and Sampling**

Recruitment and sampling are significant steps in research, and in which intersectionality can be applied. If the intersecting identities influencing the outcome(s) of interest are already known, a purposive sampling strategy could be employed to include participants with the relevant intersecting identities.<sup>25</sup> If the exploration is being done for the first time in a particular area and the researcher is completely unaware of the possible intersecting identities that might be relevant, then a maximum variation sample works the best—that is, recruiting a wide range of patients with various intersecting factors.<sup>26</sup> Moreover, participant-driven snowball sampling is a great resource for intersectionality-based research and is particularly useful for recruiting participants with stigmatized identities that they do not reveal widely, as a means to try to prevent discrimination.<sup>25</sup>

### **Data Collection**

Data collection is that phase of cardiovascular health research that requires careful consideration of the participants' intersecting identities, and being respectful of the same. Such an approach includes consideration of gender-neutral terminology, providing all possible options for gender identity (man, woman, lesbian, gay, bisexual, transgender, queer, two-spirited), ensuring that the participants have the option to indicate all of their social identities as part of the socio-demographic data (age, sex, gender, social class, race,

ethnicity, immigration status, place of residence—rural/urban), asking them via open- or close-ended questions how their social identities affect the outcome or phenomenon of interest.

### Data Analysis

Intersectionality can be thoroughly applied while analyzing research data, in the case of either quantitative or qualitative analysis. There are intersectionality-based quantitative analytical tools available, such as multiple main effects, statistical interactions, and multilevel modelling, that explore the additive, multiplicative, and multilevel effects of intersecting identities on cardiovascular outcomes, respectively.<sup>27</sup> Else-Quest and Hyde provide an excellent account of how these analyses can be applied to intersectionality-based quantitative research.<sup>27</sup> For intersectionality-informed qualitative analysis, certain frameworks have been proposed. For example, Bowleg proposed open, axial, and selective coding to reflect participants' intersectional experiences.<sup>28</sup> Similarly, Bilge has proposed performing an inductive thematic analysis followed by applying an intersectionality-informed deductive approach.<sup>29</sup> Important to note is that whatever the targeted methods, we need to ensure that these are far-reaching and sustainable.

### Conclusions

Given the increasing diversity of the Canadian cardiovascular patient population, we need to investigate the influence of intersectionality on cardiovascular health outcomes, and explore it via research. Intersectionality-driven cardiovascular research has the potential to revolutionize cardiovascular clinical practice, and improve outcomes.

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## **Chapter 4: Methods and Results**

### **Manuscript 5**

**Title:** A Scoping Review, Intersectionality-based Analysis, and Realist Synthesis of Heart Failure Telehealth Interventions for Vulnerable Populations

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# **A Scoping Review, Intersectionality-based Analysis, and Realist Synthesis of Heart Failure Telehealth Interventions for Vulnerable Populations**

## **Background**

Heart Failure (HF) is at epidemic levels among older adults in Canada (Piepoli et al., 2022). The main symptoms indicative of HF syndrome i.e. difficulty breathing, fatigue, and edema, can negatively affect all aspects of one's life, reducing patients' quality of life and causing recurrent hospital admissions (Piepoli et al., 2022). Heart Failure Disease Management Interventions (HFDMIs) enhance self-care and quality of life, as well as reduce hospital readmissions through patient education and follow up, effective treatment, psychosocial support, and enhanced access to care (Jaarsma et al., 2021; Zhao et al., 2021).

### **HF Telehealth Interventions- Exploring Complexity**

HFDMIs are complex in nature. These interventions vary widely in type and context: from interventions provided in-person in hospitals, communities or clinics, to those provided in the home remotely via telephone, email, internet or text messages (Savard et al., 2011). Telehealth was introduced to the field of HFDM in 1998 (Kotb et al., 2015). As new technologies emerged, a new form of telehealth came into play, known as telemonitoring. Telehealth includes telephone support interventions (Kotb et al., 2015), telemonitoring (use of information technology to monitor the patients at a distance) (Bakitas et al., 2017), mobile health (Athilingam & Jenkins, 2018), video consultations (Gallagher et al., 2017), wireless monitoring of heart sounds through Bluetooth and computer-based decision-making systems (Chowdhury et al., 2019).

Telehealth was supposedly intended to reduce the complexity of chronic disease management (Kvedar et al., 2014). However, telehealth interventions as a health delivery model (Alami et al.,

2018) are quite complex themselves – involving multiple components and interactions. Successful implementation requires multiple alignment of factors (Alami et al., 2018), including: organizational, clinical, administrative and technological leadership (Alami et al., 2018). Further, patient and provider preparedness and acceptance of technology is a pivotal factor that adds to this complexity, compared to traditional face-to-face interventions (Alami et al., 2018). Given the presence of complex interactions within and around HF telehealth interventions, and given their inherent complexity, it is essential to explore as to which 'contexts' and 'mechanisms' make HF telehealth interventions work or not.

This paper presents the findings of a scoping review, intersectionality-based analysis, and rapid realist synthesis around HF telehealth interventions for vulnerable groups of HF patients. This review is underpinned by the meta-theory of CR and intersectionality theory. The paper first presents an account of the current state of literature on HF telehealth interventions for vulnerable groups of HF patients. Next, a definition of intersectionality is presented followed by a discussion of the significance of intersectionality to cardiovascular diseases and an acknowledgement of a lack of research in intersectionality and HF care. The paper then presents an account of the methods employed, followed by the study findings, a discussion of the study findings, strengths and limitations of the study, and recommendations and conclusions based on the study findings.

### **HF Telehealth and Vulnerable/ Marginalized Groups of HF Patients**

When HF telehealth interventions are designed or implemented for patients from vulnerable groups, another layer of complexity is added in view of the various intersecting social identities that may lead to a lack of access to, or a lack of utilization of telehealth services. Although telehealth has been widely used amidst the pandemic (Bhatia et al., 2021), however, vulnerable

populations have experienced significant challenges in accessing and utilizing telehealth services (Shaw et al., 2021). A three-fold issue has been identified that limits our understanding of HF telehealth interventions for vulnerable groups of HF patients. First, there is very limited number of studies that have explored telehealth interventions among vulnerable/marginalized groups of HF patients. Secondly, the studies that have been done so far, those have mostly explored a single characteristic of the sample, such as ethnicity, rurality, or social class, and how it affects the access to or utilization of HF telehealth interventions (Allana et al., 2021b). Most times there is no integration of intersectionality in HF care research, which is problematic because in the absence of an intersectional lens, the cumulative disadvantage that is brought about by a complex intersection of social identities, cannot be explored (Allana et al., 2021b). Lastly, in order to address the inherent complexity of HF telehealth interventions, which is augmented by the complexity involved in dealing with marginalized patient populations, such a research approach is needed that can explore the complex interactions involved and can uncover the supposedly invisible mechanisms and contexts (Allana, 2022).

With its explanatory focus, critical realism provides a sound philosophical underpinning to the research exploring: What works for whom, how and why? Therefore, contexts and mechanisms, pertaining to effective implementation of HF telehealth interventions for vulnerable groups of HF patients, can be explored utilizing realist research methods (Allana & Clark, 2018).

Additionally, an intersectionality lens helps examine the intersecting social identities of the vulnerable groups of HF patients that put them at risk of experiencing health inequities, such as, lack of access to telehealth interventions or challenges in utilizing HF telehealth services (Allana et al, 2020). Therefore, critical realism and intersectionality theory provide philosophical and

theoretical underpinning for this research, respectively. The next section describes the concept of intersectionality and how it relates to cardiovascular care and cardiovascular care research.

### **Defining Intersectionality**

Intersectionality recognizes the various identities that each of us carries, and how these identities intersect to bring about either oppression or privilege (Allana et al., 2021a; Al-Faham et al., 2019; Hankivsky et al., 2009). As individuals, we are socially known by our social identities, such as our: age, gender, sexual orientation, race/ethnicity, religion, social class, immigration status, place of residence (rural/ urban) etc. Each of these identities can put us in a position of relative power or disadvantage; however, practically, each of these identities can also interact with other factors, thus reinforcing and compounding privilege, discrimination, and inequities (Allana et al., 2021b; Al-Faham et al., 2019; Hankivsky et al., 2009).

### **Intersectionality and Cardiovascular Diseases**

Our intersecting identities not only define us socially, but these also affect our physiological responses, our health behaviors, and our psychosocial health: all of which contribute to our risk and outcomes of cardiovascular disease (CVD) (Allana et al., 2021b). For example, older women with HF living in rural areas are less likely to follow self-care recommendations (Allana et al., 2021b; Biddle et al., 2020), or South-Asian immigrants have both increased prevalence and death rate from coronary artery disease (Allana et al., 2021b; Bainey et al., 2019), or Black lesbian women tend to have higher prevalence of cardiometabolic risk factors ( Allana et al., 2021b; Caceres et al., 2020).

All aspects of HF care i.e. self-care, informal caregiving, and clinical care are closely linked to the HF patients' intersecting identities, such as, their sex, gender, age, race or ethnicity, social

class, place of residence (rural/ urban), and their values and beliefs that are shaped socially through the influence of these identities (Allana et al., 2021a). Thus, disadvantage and inequities in HF care experienced by some of the most vulnerable groups of HF patients, can be viewed for the most part as being associated with their intersecting identities (Allana et al., 2021a).

However, this has never been explored through research yet, which is an important gap in the existing body of HF literature.

Heart failure self-care has been largely regarded as a cognitive activity that stems from a set of discrete mental capabilities. Thus, most research has explored HF patients' knowledge, decision-making ability, symptom perception, and self-efficacy (Dickson et al., 2011; Lam & Smeltzer, 2013). This disregards the fact that HF self-care is deeply rooted in patients' context and many other psychosocial factors (Dickson et al., 2013; Riegel et al., 2016) that are closely connected with intersectionality (Collins & Bilge, 2020). These include: sex and gender, social, occupational, and financial status (Clark et al., 2014), personal values and cultural beliefs (Srisuk et al., 2017), place of residence (rural/ urban) (Dang et al., 2017), spiritual practices (Heiney et al., 2020), and social support (Srisuk et al., 2017).

Moreover, HF care and its daily management is often shared between patients, their spouses and family (Kitko et al., 2020). This implies that families and other informal caregivers can support a vast range of activities related to effective HF management, including but not limited to: managing nutrition, physical activity, medication and implanted devices, smoking cessation; symptom assessment and monitoring; promoting timely access to healthcare; supporting psychosocial well-being; and assisting with end-of-life decisions (Kitko et al., 2020). Therefore, an intersectional analysis of HF self-care must extend to include family and other informal caregivers.

Health professionals' understanding of the unique needs of the vulnerable groups of HF patients is not only important, but essential in providing HF care that is relevant to the needs of these patients (Allana et al., 2020). Therefore, a profound understanding of intersectionality is required on part of clinicians (Byeon et al., 2019). Because of the growing emphasis on the role of sex and gender in determining clinical outcomes, most clinicians are aware of this and do use this knowledge in their clinical practice; however, many do not go beyond it to consider the other social identities of the patients that intersect with their sex and gender, augmenting the health disparities experienced by these patients ( Byeon et al., 2019).

### **Lack of Research in Intersectionality and HF Care**

Despite the fact that HF patients' intersecting identities can greatly influence the incidence and care of HF, intersectionality has been largely ignored in HF research in Canada and globally (Allana et al., 2021b). Studies in HF care mostly focus on singular factors and their impact on the patient outcomes- leaving both intersectionality and its effects unexplored and unacknowledged (Allana et al., 2020). A dearth of studies in intersectionality and HF urges the HF researchers to apply the principles of intersectionality to HF care research. Intersectionality can be extremely useful in exploring the health disparities experienced by HF patients, entrenched in power dynamics brought about by their intersecting social identities (Allana et al., 2021b).

### **Methods**

Use of theory-based research approaches to evaluate telehealth interventions has been urged for, in the literature (Allana & Clark, 2022). There is increasing consensus that telehealth interventions should be evaluated using complexity-driven approaches (Allana & Clark, 2022). In relation to such interventions, these approaches often bring complexity into various

aspects, including: the theoretical underpinnings of the research, the type of research questions posed, and the types of methods used.

This literature synthesis utilized a scoping review to map the existing body of literature around HF telehealth interventions for marginalized patient populations (such as racialized minorities, rural patients, gender minorities, poor or deprived etc.). A scoping review method was selected as the body of literature in this area has never been mapped before, and therefore it was important to explore as to how much research has already been done in this field. The studies that were retrieved as a result of the scoping review, then went through an intersectionality-based analysis utilizing an intersectionality-informed checklist by Ghasemi et al., 2021. This intersectionality-based analysis was meant to identify the extent to which intersectionality has been applied to this body of research. Lastly, a rapid realist synthesis was undertaken for the same body of literature to explore the underlying mechanisms and contexts that make HF telehealth interventions work or not work for marginalized groups of HF patients.

### **Scoping Review**

The search for this scoping review was systematic. The principles that were utilized to ensure a robust search included: comprehensiveness of the search, replicability of the search process, and detailed reporting of the search process (Lockwood & Oh, 2017). The databases that were searched for this review included: MEDLINE, CINAHL, Scopus, and the Cochrane Central Register of Controlled Trials. Unpublished dissertations and theses were searched through ProQuest Dissertations and Theses Global. Through these sources, a comprehensive search of the existing telehealth HFDMI research was undertaken. Key terms that were utilized for the search included: 'heart failure', 'cardiac failure', 'congestive heart failure', 'chronic heart disease', 'telehealth', 'telemonitoring', 'e-health', 'm-health', 'remote monitoring'. In these key words, different names

of the disease have been used, and the different terms that are used to describe telehealth interventions in the literature, have been included. It was particularly complex searching the studies that have been specifically done with marginalized populations. Working with an experienced librarian, we first ran the search with the terms ‘marginalized’ or ‘marginaliz\*’ with ‘heart failure’ and ‘telehealth’; however, this search did not yield very many relevant studies. In an attempt to understand this further, we went through some of the articles in this subject area that we were already aware of. Upon reviewing those articles, we realized that the issue is that most authors do not use the term ‘marginalized’ to represent underserved or vulnerable groups of HF patients. Rather, most times they indicate to the specific factors that bring about marginalization or vulnerability, in the title or abstract. For example, one of the study titles indicated social class and place of residence as key facets of their research with HF patients i.e. ‘quality of life among lower-income, urban adults with heart failure’ (Clark et al., 2003). Based on this understanding, and in consultation with a health sciences librarian, we decided to use the various relevant social identities/ factors as key words for this search, such as, gender/ sex, race/ ethnicity, place of residence (rural/ urban), social class (poor/ lower-income/ low-income), and indigeneity. A combination of all of these identities was searched for, with an ‘OR’ between them, and this was one of our search terms. Also, in an attempt to identify the most relevant articles, we added search terms such as ‘health disparity, minority, and vulnerable populations’, ‘healthcare disparities’, ‘health services accessibility’. Finally, we combined the combination of intersecting identities/ factors with the search for ‘Heart Failure’ and ‘Telehealth’ and their associated terms, using ‘AND’ in between. The search was limited to published and unpublished research in English language. An experienced health sciences librarian was consulted for this search. To ensure replicability of the search process, a detailed reporting of each step has been done.

### ***Inclusion and Exclusion Criteria***

Studies were included in the review if those were related to telehealth HFDMIs, and were undertaken with marginalized groups of HF patients, and/or with their formal or informal caregivers. To be included, the studies must be published as full papers in English, containing primary data around the development, implementation, or evaluation of a telehealth HFDMI, and the effects on the recognized HF outcomes, such as, hospital readmissions, mortality, quality of life, and self-care etc. Qualitative and mixed methods studies exploring HF patients' or health professionals' experiences of telehealth interventions were also included. Phenomena of interest were perspectives, experiences, or program-related outcomes for vulnerable/ marginalized patients living with HF, and of those involved in their care.

### ***Screening Procedures***

The screening procedures for this review were guided by the principles of transparency, inter-rater reliability, accountability and fairness, and handling biases appropriately (Lockwood & Oh, 2017). Screening was a two-step process. First, the titles and abstracts were screened, and then the entire articles were screened against the inclusion criteria. To ensure transparency, fairness, and inter-rater reliability, two of the investigators screened the articles independently, and made independent decisions for inclusion or exclusion. To handle biases, the inconclusive articles were then discussed to reach to a consensus. If consensus could not be achieved between the two reviewers, a third reviewer was available to resolve the conflict. The entire screening process was undertaken in Covidence, after importing the RIS files from the respective databases to Covidence. Results of the screening process were documented in Covidence; the studies included and excluded at various stages of screening were depicted through a PRISMA flow diagram (see Figure 1).

### ***Quality Appraisal***

The quality of the included studies was assessed based on the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). Studies have not been excluded based on quality appraisal; however, this appraisal provides a sense of the overall quality of the body of literature included in the synthesis. MMAT was deemed appropriate as studies included in this review have utilized a variety of study designs that can be appraised via MMAT.

### ***Data Extraction***

For each published study included in the scoping review, study characteristics were extracted, such as, authors, year of publication, and the country where the research was carried out. Based on a preliminary data extraction exercise, categories were developed that guided data extraction.

Using a standardized data extraction form, the following data were extracted from the included studies: 1) title and year of the study, 2) country where the study was undertaken 3) study design, 4) vulnerable population studied, 5) type of telehealth intervention implemented/ evaluated.

Next, each study was read thoroughly and the intersectionality-based checklist by Ghasemi et al. (2021) was applied, whereby a yes/no response was marked for each question on the checklist and the relevant supporting data was extracted. Data was also extracted around the contextual factors and mechanisms that made these interventions work or not, along with the intervention outcomes, for the purpose of rapid realist synthesis.

### ***Data Synthesis***

The intersectionality-based analysis was undertaken using a structured checklist by Ghasemi et al. (2021) that contains a total of 38 questions, categorized into three sections i.e. Problem identification, Design and implementation, and Evaluation. Each section contains a

number of categories, which are groups of 2-3 relevant questions. Each question of the checklist could be answered either with yes or no. Each article was read in full to answer each question of the checklist. Once all questions were answered, the number of 'yes' and 'no' responses were calculated for each question. The scores were then added for each category and the respective percentages of 'yes' and 'no' responses were calculated for each category of questions. Also, the supporting data extracted from the included studies were synthesized to present an account of how well intersectionality has been integrated across various stages of research.

This dissertation also employed a rapid realist synthesis, which is methodologically a bit different than the realist synthesis. Although both the methods are philosophically underpinned by a critical realist lens and are largely similar in their approach toward identification of the underlying mechanisms; however, there are nuanced differences in the practical application of the two methods. Realist synthesis utilizes primary data as the most important source for the formulation of program theory; however, a rapid realist synthesis may not include primary data collection due to time or resource constraints. Secondly, as opposed to the realist synthesis approach that utilizes a vast range of literature sources and does not limit itself to academic literature only, a rapid realist synthesis may or may not include grey literature. Due to the limited time and resources that we had for this particular dissertation, a rapid realist synthesis approach was deemed more appropriate.

For this rapid realist synthesis, academic literature systematically searched through academic databases was included. The articles were read to identify the effects of HF telehealth interventions for vulnerable populations as well as the underlying mechanisms and contexts that brought those effects on surface. In order to identify the underlying mechanisms and contexts from the included studies, retroduction was used. Retroduction is a method of analysis, whereby

first a pertinent observation/ effect is identified, and then the researcher moves backward to understand the underlying mechanism or the causal reasoning (Mukumbang et al., 2021).

Contexts and mechanisms related data extracted from the included studies were synthesized by identifying the reoccurring themes across studies.

## **Results**

Figure 1 illustrates the PRISMA diagram for this scoping review and depicts the total number of studies screened, included and excluded at various stages of the screening process. 914 studies were retrieved as a result of the searches ran in the selected databases. After removing 242 duplicates, the titles and abstracts of the remaining 672 studies were reviewed. Based on this initial screening, 97 studies were selected for full-text screening. Each article was read thoroughly to examine if it fits the inclusion criteria; based on full-text screening, 22 studies were selected to be included in this review. 75 studies were excluded at this final stage as they did not fit the inclusion criteria due to the various reasons listed in the PRISMA flowchart in figure 1.



Figure 1: PRISMA Diagram

Table 1 presents the characteristics of included studies in this review. Out of the 22 included studies, 19 were undertaken in USA (Bakhshi et al., 2011; Bakitas et al., 2017; Bakitas et al., 2020; Caban, 2019; Dang et al., 2017; Davis et al., 2015; Dionne-Odom et al., 2020; Heiney et al., 2020; Lefler et al., 2018; Liu et al., 2009; Newell et al., 2017; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Riegel et al., 2006; Riley et al., 2015; Rosen et al., 2016; Sammour et al., 2021; Soran et al., 2008; Turchioe et al., 2020). The rest of the three studies were conducted in Canada (Jaana & Sherrard, 2019), Australia (Krum et al., 2012), and Thailand (Srisuk et al., 2017). Eight studies out of 22 (Bakitas et al. 2020; Dang et al., 2017; Dionne-Odom et al., 2020; Krum et al., 2012; Pekmazaris et al., 2019; Riegel et al., 2006; Soran et al., 2008; Srisuk et al.,

2017) have used a randomized controlled trial to demonstrate the effectiveness of telehealth interventions for vulnerable groups of HF patients, whereas, pre-post design has been used by two studies (Riley et al., 2015; Rosen et al., 2016). Moreover, cross sectional or quantitative survey design has been utilized by three (Jaana & Sherrard, 2019; Liu et al., 2009; Turchioe et al., 2020), and retrospective data collection and analysis has been used by three (Caban, 2019; Davis et al., 2017; Sammour et al., 2021). There are two feasibility trials (Bakhshi et al., 2011; Bakitas et al., 2017). Whereas, qualitative and mixed methods have been used by two (Heiney et al., 2020; Pekmazaris et al., 2016) and one study (Lefler et al., 2018), respectively. One study only reported the development and implementation of a telehealth program for HF patient, with no associated evaluation (Newell et al., 2017). In terms of the vulnerable/ marginalized populations, Blacks, Hispanics, and rural HF patients were most commonly studied in the included studies (Bakitas et al., 2017; Bakitas et al., 2020; Caban, 2019; Dang et al., 2017; Dionne-Odom et al., 2020; Heiney et al., 2020; Jaana & Sherrard, 2019; Krum et al., 2012; Newell et al., 2017; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Riegel et al., 2006; Riley et al., 2015; Sammour et al., 2021; Soran et al., 2008; Srisuk et al., 2017; Turchioe et al., 2020). Other vulnerable populations included underserved patients, those with low-income and low educational levels (Bakhshi et al., 2011; Davis et al., 2015; Lefler et al., 2018; Liu et al., 2009; Rosen et al., 2016). Various types of telehealth interventions were developed, implemented, or evaluated, including: 1) telephone support interventions (n= 6 studies), remote monitoring interventions (n= 9 studies), video consultations (n= 3 studies), remote monitoring and video consultations (n=2 studies), telephone case management (n= 1 study), remote monitoring and telephone-based symptom response system (n= 1 study) (see Table 1).

Table 1: Characteristics of Included Studies

<b>S. No.</b>	<b>Author (year)</b>	<b>Study title</b>	<b>Country</b>	<b>Study Design</b>	<b>Vulnerable Population Studied</b>	<b>Type of Telehealth Interventions</b>
1.	Bakitas et al., 2017	Engaging patients and families to create a Feasible clinical trial integrating palliative and heart failure care: results of the Enable CHF-PC pilot clinical trial	USA	Feasibility trial	African Americans, rural and urban population, low educational level	Telephonic nurse coach sessions and monthly calls
2.	Bakitas et al. 2020	Effect of an early palliative care telehealth intervention Vs usual care on patients with heart failure: The enable CHF-PC randomized clinical trial	USA	Randomized clinical trial	African Americans, rural and urban population, low educational level	Telephonic nurse coach sessions and monthly calls
3.	Newell et al. 2017	Design and initial results of the Minneapolis heart Institute tele heart program	USA	Tele health intervention design and implementation	Rural population	Video consultations
4.	Pekmazaris et al. 2019	A randomized controlled trial comparing telehealth Self-management to standard outpatient management In underserved black and Hispanic patients living with heart failure	USA	Randomized controlled trail	Underserved Blacks and Hispanics	Remote monitoring and Video consultations
5.	Pekmezaris et al. 2016	A qualitative analysis to optimize a Telemonitoring intervention for heart failure Patients from disparity communities	USA	Qualitative study-Community based participatory research approach	Lower income Blacks and Hispanics	Remote monitoring and Video consultations
6.	Dang et al. 2017	Mobile phone intervention for heart failure In a minority urban county	USA	Randomized controlled trial	Blacks and Hispanics	Mobile phone-based tele monitoring

	hospital population: Usability and patient perspectives					
7. Dionne-odom et al. 2020	Effects of a telehealth early palliative care intervention for family caregivers of persons with advanced heart failure: The enable CHF-PC randomized clinical trial	USA	Randomized clinical trial	African Americans, rural and urban population, low educational level	Telephonic nurse coach sessions and monthly calls	
8. Rosen et al. 2016	Increasing self-knowledge: utilizing tele-coaching for patients with congestive heart failure	USA	Pre-test and post-test design	Low-income patients	Video consultations	
9. Riegel et al. 2006	Randomized controlled trial of telephone case Management in Hispanics of Mexican origin With heart failure	USA (US-Mexico border)	Randomized controlled trial	Hispanics of Mexican origin	Telephone case management including: a decision support software, telephone support.	
10 Turchioe et al. 2020	Older adults can successfully monitor symptoms using An inclusively designed mobile application	USA	Cross sectional feasibility study	English and Spanish speaking older adults	Mobile application to report symptoms	
11 Heiney et al. 2020	A smartphone app for self-management of heart failure in older African Americans: feasibility and usability study	USA	Qualitative study- Development and feasibility test of mHealth app	African Americans	Mobile application for weight monitoring, health messages, and journaling.	
12 Jaana & Sherrard, 2019	Rural-urban comparison of telehome monitoring for patients with chronic heart failure	Canada	Cross-sectional study	Rural population	Remote monitoring via mobile phone	

13	Bakhshi et al. 2011	Congestive heart failure home monitoring pilot study in urban Denver	USA	Feasibility Trial	Low-income patients	Remote monitoring
14	Liu et al. 2009	Pervasive telemonitoring for patients living with chronic Heart failure: a quantitative study of telemedicine Acceptance	USA	Quantitative survey method	Medically underserved urban population	Telemonitoring
15	Srisuk et al. 2017	Randomized controlled trial of family-based education for patients with heart failure and their carers	Thailand	Randomized controlled trial	Rural population	Telephone support
16	Caban, 2019	The use of home telemonitoring for Heart Failure Management Among Hispanics, Non-Hispanic Blacks, and Non-Hispanic Whites	USA	Retrospective quantitative study	Hispanics, Non-Hispanic Blacks, and Non-Hispanic Whites	Home telemonitoring
17	Soran et al. 2008	A Randomized Clinical Trial of the Clinical Effects of Enhanced Heart Failure Monitoring Using a Computer-Based Telephonic Monitoring System in Older Minorities and Women	USA	Randomized controlled trial	Elderly women, African Americans, Hispanics	Telemonitoring and telephone-based symptom response system
18	Riley et al. 2015	Program Evaluation of Remote Heart Failure Monitoring: Healthcare Utilization Analysis in a Rural Regional Medical Center	USA	Pre-post design-Development and testing of remote monitoring intervention	Underserved patients in rural communities	Remote monitoring
19	Krum et al. 2012	Telephone Support to Rural and Remote Patients with Heart Failure: The Chronic Heart Failure Assessment by Telephone (CHAT) study	Australia	Randomized controlled trial	Rural and remote communities of Australia	Telephone support
20	Lefler et al. 2018	Evaluating the Use of Mobile Health Technology in Older Adults With Heart Failure: Mixed-Methods Study	USA	Mixed-Methods Study	Low educational level	Remote monitoring and

						telephone support
21	Davis et al. 2015	Feasibility and Acute Care Utilization Outcomes of a Post-Acute Transitional Telemonitoring Program for Underserved Chronic Disease Patients	USA	Retrospective cohort design	Underserved patients (those having no insurance, low income seniors, Medi care recipients)	Remote monitoring
22	Sammour et al. 2021	Comparison of video and telephone visits in outpatients with heart failure	USA	Retrospective Study Design	African Americans, Low-income, low educational level	Video and telephone consultations

*Table 2: Synthesis of Application of Intersectionality In Included Studies*

	Possible response to each question	Intersecting Categories	Multilevel Analysis	Power	Reflexivity	Time & Space	Diverse Knowledge	Social Justice & Equity	Overall
Problem Identification	Yes	43 (65.15%)	33 (75%)	23 (34.84%)	10 (45.45%)	6 (27.27%)	14 (31.81%)	1 (2.27%)	130 (42.2%)
	No	23 (34.84%)	11 (25%)	43 (65.15%)	12 (54.54%)	16 (72.72%)	30 (68.18%)	43 (97.7%)	178 (57.8%)
	Unclear Number of questions <sup>a</sup>	<b>66</b>	<b>44</b>	<b>66</b>	<b>22</b>	<b>22</b>	<b>44</b>	<b>44</b>	<b>308</b>
Design & implementation	Yes	39 (88.63%)	9 (40.9%)	40 (30.76%)	5 (22.72%)	18 (81.81%)	5 (11.36%)	25 (56.81%)	141 (42.9%)
	No	5 (11.36%)	13 (59.1%)	90 (69.23%)	17 (77.27%)	4 (18.18%)	39 (88.63%)	19 (43.18%)	187 (57.1%)
	Unclear Number of questions <sup>a</sup>	<b>44</b>	<b>22</b>	<b>130</b>	<b>22</b>	<b>22</b>	<b>44</b>	<b>44</b>	<b>328</b>
Evaluation	Yes	1 (5.26%)	5 (26.31%)	19 (46.34%)	7 (36.84%)	N/A	15 (36.58%)	6 (14.63%)	53 (29.44%)
	No	18 (94.73%)	14(73.68%)	22 (53.65%)	12 (63.15%)	N/A	26 (63.41%)	35 (85.36%)	127 (70.55%)
	Unclear Number of questions <sup>a</sup>	<b>19</b>	<b>19</b>	<b>41</b>	<b>19</b>		<b>41</b>	<b>41</b>	<b>180</b>



### **Quality of the Included Studies:**

As per the quality appraisal through MMAT, the overall body of studies included in the review was of high quality. All of the randomized controlled trials (RCTs) had appropriate randomization, comparable groups, complete outcome data, and adherence to the intervention. However, blinding of the assessors was only performed in three studies (Bakitas et al., 2020; Dionne-Odom et al., 2020; Srisuk et al., 2017). Considering the nature of the intervention, blinding was not possible in the other RCTs. For the quantitative descriptive studies, sampling strategy was appropriate, samples were representative of target populations, and the statistical analyses were appropriate. However, appropriate outcome measures were only selected in a few studies (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Lefler et al., 2018; Riley et al., 2015; Turchioe et al., 2020). For the non-randomized feasibility or pre-post design studies, samples were representative, measurements were appropriate, outcome data was complete, confounders were accounted for, and the intervention was administered as intended (Bakhshi et al., 2011; Bakitas et al., 2017; Riley et al., 2015; Rosen et al., 2016). For the two qualitative studies (Heiney et al., 2020; Pekmazaris et al., 2020), the appropriateness of qualitative approach and data collection methods was evident. Findings were adequately derived from the data, the interpretation of findings was substantiated by data, and all of the research processes were coherent. The only mixed-methods study included in this review (Lefler et al., 2018) integrated the qualitative and the quantitative well in relevance to the study questions. The authors also integrated and interpreted the findings from the qualitative and quantitative components well, indicating to the similarities and differences.

### **Intersectionality-based Analysis:**

Overall, the principles of intersectionality were mainly addressed in the ‘problem identification’ and ‘design and implementation’ stages. At the evaluation stage, there were very few studies that had incorporated intersectionality-based principles (Caban, 2019; Dang et al., 2017; Davis et al., 2015; Lefler et al., 2018; Pekmazaris et al., 2016) (see Table 2). Overall, about 42.2% of the responses indicated that studies incorporated the principles of intersectionality at the ‘problem identification’ stage, followed by 42.9% and 29.44% responses indicating incorporation of these principles at the ‘design and implementation’ and ‘evaluation’ stages, respectively. At the ‘problem identification’ stage, most authors identified ‘intersecting categories’ i.e. a combination of different social factors that caused the problem under study, and they indicated to the most vulnerable population they were interested in studying (65.15% positive responses) (Bakhshi et al., 2011; Bakitas et al., 2017; Bakitas et al., 2020; Caban, 2019; Davis et al., 2015; Heiney et al., 2020; Jaana & Sherrard, 2019; Krum et al., 2012; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Reigel et al., 2006; Soran et al., 2008; Turchioe et al., 2020). In addition to that, they also talked about various factors at the individual, interpersonal, and organizational levels (multi-level analysis) as part of problem identification (75% positive responses) (Bakhshi et al., 2011; Bakitas et al., 2017; Bakitas et al., 2020; Caban, 2019; Davis et al., 2015; Heiney et al., 2020; Jaana & Sherrard, 2019; Krum et al., 2012; Liu et al., 2009; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Reigel et al., 2006; Soran et al., 2008). However, only about 35% of the responses indicated to stakeholders’ participation in the process of problem identification (power) (Heiney et al., 2020; Lefler et al., 2018; Pekmazaris et al., 2016; Riegel et al., 2006; Srisuk et al., 2017). Researchers’ reflexivity was accounted for at the ‘problem identification stage’ (45.45% positive responses) (Bakitas et al., 2017; Bakitas et al., 2020; Caban, 2019; Heiney et al., 2020; Lefler et

al., 2018; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Riegel et al., 2006; Soran et al., 2008; Srisuk et al., 2017; Turchioe et al., 2020). Problem framing over time and space was rarely used (27.27%) (Bakitas et al., 2017; Bakitas et al., 2020; Jaana & Sherrard, 2019; Srisuk et al., 2017). Under the domain of ‘diverse knowledge’, only about 31% responses indicated that marginalized peoples’ perspectives were used in the process of problem identification or diverse sources of knowledge were utilized (Heiney et al., 2020; Lefler et al., 2018; Pekmazaris et al., 2016; Riegel et al., 2006; Srisuk et al., 2017). Under ‘social justice and equity’, only one response was positive as only one author considered social justice and access issues i.e. unavailability of HF telehealth programs in community settings via primary care physicians’ office, and applied it at the various stages of the research process (Soran et al., 2008).

At the ‘design and implementation’ stage, there were about 65% positive responses for ‘intersecting categories’ as most interventions were selected using intersectional perspective and most target groups represented experiences of diverse/ vulnerable groups of patients. However, incorporation of the principles of ‘multi-level analysis’ (40.9%), ‘power’ (30.76%), ‘reflexivity’ (22.72%), and ‘diverse knowledge’ (11.36%) was significantly less at this stage. Only four studies involved stakeholders from affected populations as part of the intervention development or implementation (Heiney et al., 2020; Lefler et al., 2018; Pekmazaris et al., 2016; Riegel et al., 2016). About 57% responses at this stage indicated that the principle of ‘social justice and equity’ was incorporated in the selected studies. Though many interventions included in this review did not lead to further inequalities; however, none of the studies mentioned explicitly that those interventions were designed and implemented to reduce inequalities. It was inferred in a few cases that the intervention intended at increasing access to telehealth for a vulnerable group of patients (Bakhshi et al., 2011; Krum et al., 2012; Srisuk et al., 2017).

As mentioned earlier, the least application of intersectionality principles was observed at the ‘evaluation’ stage. Only six studies had a measure of success determined on the basis of reducing inequalities, such as usability and user friendliness of the telehealth interventions (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Lefler et al., 2018; Riley et al., 2015; Turchioe et al., 2020). Firsthand data was collected from the vulnerable groups of HF patients, around these measures. All other studies had defined outcomes based on clinical variables such as cardiovascular mortality, readmissions etc. Additionally, only one study measured intersectional factors at the ‘evaluation stage’. Caban (2019) ran a multiple regression analysis and examined the influence of a number of intersecting identities on the outcome measures. Many other studies collected various demographic data; however, they did not utilize that data as part of their analysis, or if they did, they only looked at the influence of each individual factor on the outcome of interest. For ‘multi-level analysis’, only 26.31% positive responses came in. These were the studies that have looked at the outcomes at the level of family or healthcare system (cost, length of stay) in addition to the individual level outcomes (Bakhshi et al., 2011; Riegel et al., 2016; Srisuk et al., 2017). However, majority of the included studies had only measured outcomes at the individual level. Under ‘power’, 46.34% responses depicted that affected groups were involved in the evaluation process (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Lefler et al., 2018; Pekmazaris et al., 2016; Riley et al., 2015; Turchioe et al., 2020). Although less than 50% responses are positive in this category; however, it is encouraging that vulnerable patients’ feedback is being considered and collected and their voices are being heard.

### **Rapid Realist Synthesis:**

A rapid realist synthesis was undertaken to identify the contexts and mechanisms that make HF telehealth interventions work or not for vulnerable groups of HF patients. This realist synthesis

has brought about important contextual realities and mechanisms, which can be of help in improving HF telehealth programs for vulnerable patient populations.

Key Contexts:

#### 1. Family Members' Involvement in Telehealth/ Remote Monitoring Programs

Family caregiving is an integral part of HF care. This review has demonstrated that telehealth programs are successful for vulnerable groups of HF patients when their family members are involved in training as well as in the execution of telehealth/ remote monitoring programs. Riley et al. (2015) involved family members of rural underserved HF patients in training as well as in telemonitoring, and in sending the recorded measurements to the study team via mobile application. As part of another study, the Community Advisory Board, which constituted lower income Blacks and Hispanic HF patients, suggested the research team to involve a family member or friend who can assist the patient in using remote monitoring equipment (Pekmazaris et al., 2016). Another study included in this review has exclusively tested a family-based telehealth intervention, whereby both HF patients and their family caregivers were the study participants (Srisuk et al., 2017). This study was undertaken in rural Thailand and the findings demonstrated that this intervention was highly successful. Family members' participation and support was instrumental to the success of this intervention (Srisuk et al., 2017). Bakitas et al. (2017), Bakitas et al. (2020), and Dionne-Odom et al. (2020) tested a palliative care intervention for HF patients, which was a combination of in-person and telehealth components. This intervention included patients' family caregivers throughout, and came out to be successful.

#### 2. Training of Health Professionals

The review findings suggest that as much as it is important to train patients and family caregivers for the telehealth program, it is equally important to train the health professionals as well.

Bakitas et al. (2017) reported that they provided 20 hours of training to the nurse coaches which included role plays of dealing effectively with the patients via telehealth intervention. Dang et al. (2017) have also strongly suggested staff training based on their experience with the telehealth intervention delivery as part of their study with Black and Hispanic patients with HF. Another study reported that the primary doctors did not respond and act appropriately in case of clinical deterioration of HF patients who were remotely monitored in this study (Soran et al., 2008). Based on that, Soran et al. (2008) recommend training physicians and other health professionals who are involved in the delivery of telehealth/ remote monitoring interventions or who are receiving the patient data, and are supposed to act promptly and appropriately in case of clinical deterioration. Rosen et al. (2016) undertook an interesting telehealth intervention, which was delivered primarily by social workers. These social workers were trained extensively around the health-related aspects of HF care, while they brought in their expertise in social aspects of care.

### 3. Significance of an In-Person Component along with the Telehealth/ Remote Monitoring Program

One of the significant findings of this review was the fact that in many of the studies, participants appreciated or requested for at least one in-person meeting or interaction with their health providers along with a telehealth or remote monitoring component. Those interventions that were a combination of both in-person and telehealth components were also found to be relatively more effective (Bakitas et al., 2017; Bakitas et al., 2020; Davis et al., 2015; Dionne-Odom et al., 2020; Rosen et al., 2016; Srisuk et al., 2017). The in-person components in most cases were meant to build rapport with the patients and for the purpose of training or education. The Community Advisory Board consisting of lower income Black and Hispanic patients as part of the study by Pekmazaris et al. (2016) suggested to arrange the first in-person meeting of the HF patients with

the telemonitoring nurse. Comparing their study findings with other studies in this area of research, Soran et al. (2008) strongly suggested including a home visit even if it is only possible once.

#### 4. One Size Doesn't Fit All- Personalized Tailoring of Telehealth Interventions

In the current review, several studies have emphasized the need of personalized and tailored interventions for vulnerable groups of HF patients (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Pekmazaris et al., 2016; Riegel et al., 2006; Soran et al., 2008; Srisuk et al., 2017; Turchioe et al., 2020). Riegel et al. (2006) undertook a trial of telephone case management with Hispanic HF patients of Mexican origin. They tailored the intervention to be culturally appropriate and specific to the needs of this particular patient population through bilingual and bicultural health professionals, cultural values of care, trust, family inclusion, and problem solving integrated within the intervention (Riegel et al., 2006). Another example of personalized and tailored telehealth intervention included as part of this review is the one by Srisuk et al. (2017). They offered a HF telehealth intervention for rural Thai patients, and culturally tailored it to involve family caregivers with HF patients at each stage of the intervention delivery, so as to make it more relevant for this group of patients. They also modified the intervention content, including pictures and text that reflected Thai culture. The manual and DVD used as part of the intervention were translated to Thai language. Pekmazaris et al. (2016) went even a step further to make their intervention personalized and tailored for the vulnerable groups of HF patients in their study. As part of their community-based participatory research approach, they recruited a sample of Black and Hispanic HF patients to form a Community Advisory Board, and sought input from them at several stages to develop and adapt a user-centred intervention. Based on the patients' feedback, specific changes were made in the intervention delivery and equipment.

Besides these three studies, other authors have also recommended using a personalized approach to interventions, such as, based on their findings, Davis et al. (2015) recommended personalized consistent feedback for HF patients by the telehealth nurse or physician. Another study by Dang et al. (2017) demonstrated personalization by providing a choice to the patients to choose their preferred time and language for receiving the daily questions. Patients in this study also recommended the questions to be more patient-specific rather than general. Heiney et al. (2020) also made their mobile health intervention personalized for African American patients by involving these patients in the app development process as well as by making intervention content more relevant to their cultural values. One important issue highlighted by Pekmazaris et al. (2016) is the unique characteristics of vulnerable groups of HF patients such as younger age for the incidence of HF and presence of more co-morbidities as compared to the general population. These unique characteristics, along with specific cultural values, beliefs, and language call for specifically tailored telehealth programs for vulnerable groups of HF patients.

##### 5. Contextual Realities of Health Care Systems

Telehealth interventions are performed within the broader healthcare system; therefore, these are bound to be affected by the contextual realities of the healthcare systems. In a study by Lefler et al. (2018), participants alluded to unavailability of health professionals to respond to them or unsatisfactory responses by them, when the patient needed guidance around managing their symptoms. This could potentially lead to clinical deterioration and could result into the very outcomes that we are trying to prevent through the use of telehealth interventions. Dang et al. (2017) suggested using more health professionals and a variety of them (nurses, doctors, dieticians) to be better able to support HF patients via telehealth interventions.

Another very important contextual reality has been discussed by Soran et al. (2008). They indicated to the fact that a typical heart failure patient is not seen by a cardiologist or a chronic care team, rather such patients present often to primary care physicians in community settings. This holds true for most vulnerable patients with HF. However, most disease management programs including telehealth interventions are run in large academic centers (Soran et al., 2008). HF telehealth interventions need to be tailored accordingly and must be offered in community settings via primary care physicians' offices, to be able to capture the vulnerable populations.

Soran et al. (2008) also alluded to another important fact that is part of the context. They indicated that when telehealth interventions are not integrated in the workflow practices, then it becomes difficult to run these interventions successfully. Riley et al. (2015) also made important recommendations in this regard. They suggested that to be useful, telemonitoring data must be incorporated in the care team's workflow, such that the health care providers should know when and how to intervene based on the data received from the patient via telemonitoring (Riley et al., 2015).

#### 6. Equipment related Issues

As part of this review, some studies have highlighted the equipment related issues that interfered with the delivery of telehealth interventions. Most times, these issues were highlighted by the HF patients themselves. Some participants described setting up the equipment as a tough task, such as levelling the weighing scale, setting up the i-Pad etc. (Lefler et al., 2018). In another study by Dang et al. (2017), Black and Hispanic HF patients suggested having bigger font sizes on screen, accurate translation of equipment names in Spanish, slowing down the speed of verbal instructions provided during telemonitoring, and decreasing the use of medical jargons.

## 7. Technical Issues

Since telehealth and remote monitoring interventions largely rely on internet connectivity for the purpose of virtual consultations as well as for data transmission, internet connectivity problem came out to be one of the biggest technical issues that hampered the delivery of telehealth and remote monitoring interventions (Pekmazaris et al., 2016; Riley et al., 2015). Riley et al. (2015) reported working proactively to ensure adequate network stability required for the transmission of patient data. Another important technical context was discussed by Dang et al. (2017) based on their experience with web browser messaging. They suggested that text messages are not only more user-friendly as compared to web browser messages, but they also require less data and therefore pose lesser connectivity challenges.

### Key Mechanisms:

#### 1. Simplified Interventions Work versus Too Complex

This review has demonstrated that when it comes to HF telehealth interventions for vulnerable patient populations, simpler interventions might work better due to the low levels of education, health literacy, and digital literacy among these groups of patients. For example, Riley et al. (2015) suggested this making an argument that rural patients find remote monitoring interventions too complex. Lefler et al. (2018) suggested the same in view of HF patients' cognitive changes, poor health literacy, and patients' inclinations. Bakhshi et al. (2011) also advocated for simplicity in telehealth and remote monitoring interventions. While dealing with a population with very low educational levels, Bakhshi et al. (2011) ensured that the daily weight data be transmitted automatically to the health providers via servers so that remote monitoring remains simple for these patients.

## 2. Simplified Patient Training Increases Confidence for the Use of Telehealth/ Remote Monitoring Equipment

Those telehealth programs were found to be effective for vulnerable groups of HF patients, whereby a simplified and easy to understand training was provided to them to be able to use telehealth/ remote monitoring equipment effectively. Simplified training was easy for them to understand and thus led to an increased confidence in using the telehealth/ remote monitoring equipment (Bakitas et al., 2017; Caban, 2019; Dang et al., 2017; Pekmazaris et al., 2016). Caban (2019) provided training to their participants, most of whom belonged to racialized minorities i.e. Blacks and Hispanics; they taught even the simplest things to the patients such as putting on a blood pressure cuff, using a digital scale, measuring oxygen saturation, and sending the information electronically to their health providers. Similarly, Dang et al. (2017) describe in their manuscript that their study participants, most of whom had low educational levels and were either African Americans or White Hispanics, provided feedback that even after the initial training, it was difficult for them to use the Web browser messaging system. These HF patients requested for extra training; in response to this request, Dang et al. (2017) provided them one-on-one training for using web browser on a mobile phone. Additionally, they provided them a step by step instruction manual with pictures, so that the participants can follow instructions easily. In another study, whereby the participants had similar demographic characteristics and lower levels of health literacy, they expressed frustration and dissatisfaction in completing some of the measures and they made a request for more pictorial, colorful, and less text-heavy training material (Bakitas et al., 2017). In one of the other studies, lower income Blacks and Hispanic HF patients suggested to increase training time as well as to offer in-person training for equipment

use, so that the telehealth program can be made more effective for them (Pekmazaris et al., 2016).

### 3. Sense of Security, and Increased Comfort with Managing Symptoms Reinforces the Use of Telemonitoring

A number of included studies indicated to the fact that telemonitoring interventions increased HF patients' sense of security. For instance, in a study by Lefler et al. (2018), a theme came up 'watching over me', whereby the participants described a sense of confidence that emerged with the use of telemonitoring. This confidence came from the feeling that someone experienced and knowledgeable in healthcare is watching over them, and therefore led them to use telemonitoring more effectively. Participants in another study discussed a similar sense of security (Davis et al., 2015). Another important theme that came up in Lefler et al. (2018) study was around an increased level of comfort in managing HF symptoms and an awareness of one's own health, that was experienced when patients used telemonitoring regularly. This comfort and awareness reinforced their use of telemonitoring every day. Liu (2009) has demonstrated that HF patients' confidence and proficiency in using technology and their perception of ease of use significantly affects their perception of usefulness of telehealth interventions.

## **Discussion**

We examined the application of intersectionality in designing, implementing, and evaluating HF telehealth programs for vulnerable populations. This review has the potential to inform researchers, practitioners, and policy-makers about the use of intersectionality as an innovative and promising approach to reduce health inequities for vulnerable populations, and highlight the gaps in this area of research.

As per the study findings, all the included studies were undertaken between 2008 and 2021. This depicts that health inequities experienced by vulnerable groups of HF patients have only gained researchers' attention over the last decade or so. Therefore, these issues need to be addressed more often in research around HF telehealth interventions, especially exploring these interventions among various groups of vulnerable/ marginalized HF patients. Moreover, most studies included in this review were conducted in USA. Though these studies provide rich data around the phenomenon of interest and have explored it among various vulnerable populations; however, they are limited to one particular context. More research along the same lines is required to be undertaken in other contexts, so as to produce context-specific findings, as context matters a lot when it comes to health interventions, whereby several aspects of the healthcare system affect the delivery of interventions (Allana & Clark, 2018).

Another important finding that has come to light as a result of this review is around the choice of methods to explore this important phenomenon. Only two studies have employed qualitative methods and one study has utilized mixed methods. More studies using interpretive or realist methods are needed to explore the health inequities experienced by marginalized groups of HF patients and to identify the contexts and mechanisms that make these interventions work or not for vulnerable patients, respectively.

An analysis of vulnerable populations with whom the included studies have been undertaken shows that there are a few specific populations that have been involved in most studies as participants, such as, African Americans, Hispanics, and rural low-income populations. Definitely, these are all very important and vulnerable populations, and these studies have brought about important findings. However, there are other vulnerable populations as well that have not been involved as yet to explore this particular phenomenon; these include: other

racialized minorities such as South Asians, Chinese etc., gender minorities, immigrants and refugees, women with various intersecting social identities, indigenous peoples etc.

In terms of the types of telehealth interventions, a variety of interventions have been explored, such as telephone support, video consultations, remote monitoring interventions, and telephone case management. This provides specific findings around how each of these telehealth interventions can be tailored to make them more relevant to the needs of vulnerable groups of HF patients.

### **Intersectionality-based Analysis**

This review has generated important findings based on the intersectionality-based analysis. As per the intersectionality-based analysis, only one of the included studies has analyzed participants' multiple intersecting identities to identify their effects on outcomes of interest (Caban, 2019), whereas the other nine studies that recruited patients with intersecting social identities (Bakitas et al., 2017; Bakitas et al., 2017; Dionne-Odom et al., 2020; Liu et al., 2009; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Riley et al., 2015; Soran et al., 2008; Sammour et al., 2021), they did not bring intersectionality to their data analysis, which could have generated significant and interesting findings around how various intersecting identities affect HF related outcomes in the context of telehealth interventions, or how these identities affect access to and utilization of HF telehealth programs. None of the studies was theoretically underpinned by intersectionality theory or grounded in critical philosophy. Research that is grounded in critical philosophy helps uncover underlying power structures that lead to health inequities (Allana & Clark, 2018; Bhaskar et al., 1998). In the absence of a sound theoretical and philosophical underpinning, it is difficult to get to the heart of the matter and explore the

nuanced power dynamics and the resulting health disparities for vulnerable populations (Allana et al., 2021b).

The review findings demonstrate that though the principles of intersectionality have been applied to the stages of problem identification and intervention development and implementation; however, very few studies have applied these principles at the stage of intervention evaluation (Caban, 2019; Dang et al., 2017; Davis et al., 2015; Lefler et al., 2018; Pekmazaris et al., 2016). This is crucial because unless we evaluate telehealth programs from an intersectional perspective, we wouldn't know as to how relevant our interventions are for the vulnerable groups of HF patients and how can we tailor those to meet the specific needs of these patient populations.

Very few studies included in the review involved stakeholders including vulnerable populations as part of the problem identification and implementation of the intervention (Lefler et al., 2018; Riegel et al., 2006; Srisuk et al., 2017). This is concerning because the very aim of developing and implementing interventions for vulnerable populations is to make these interventions as much relevant and specific to their needs as possible. Therefore, without having them on-board and without hearing their voices, this aim cannot be achieved (Ghasemi et al., 2021). However, an encouraging finding is that six studies included in this review (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Lefler et al., 2018; Riley et al., 2015; Turchioe et al., 2020) did collect vulnerable patients' feedback on the usability and user-friendliness of the telehealth and telemonitoring intervention offered to them as part of the study. This data can be used to improve future telehealth interventions for these groups of HF patients.

Social justice and equity are important principles to be considered when researching with vulnerable populations. Although, as part of the current review, few authors talked about it in

their manuscripts (Bakhshi et al., 2011; Davis et al., 2015; Heiney et al., 2020; Jaana & Sherrard, 2019; Krum et al., 2013; Newell et al., 2017; Pekmazaris et al., 2016; Pekmazaris et al., 2019; Riegel et al., 2006; Riley et al., 2015; Sammour et al., 2020; Soran et al., 2008); however, they simply stated these issues in the background section or at most applied these to patient recruitment. Social justice and equity is a theoretical lens, which if appropriately and fully applied to the research around vulnerable populations, has the potential to uncover structures of power that give rise to various health inequities (Moradi & Grzanka, 2017).

When interventions are meant to reduce health inequities, the researchers tend to measure this construct in their outcomes of interest. Only six out of the 22 studies in this review had a measure of success based on reducing health inequities (Dang et al., 2017; Davis et al., 2015; Heiney et al., 2020; Lefler et al., 2018; Riley et al., 2015; Turchioe et al., 2020). This is concerning because in the absence of outcome measures specific to health inequities, objective or subjective data cannot be collected around various health inequities experienced by vulnerable groups of HF patients. Also, a majority of the studies included in this review measured outcomes only at the individual level. Health inequities can occur at various levels including micro, meso, and macro levels (Ghasemi et al., 2021). Therefore, research around vulnerable populations, exploring health disparities, must measure outcomes at individual, interpersonal, organizational, and health system levels.

### **Realist Synthesis**

Inequities in access to and utilization of telehealth services is significantly relevant for vulnerable groups of patients. Vulnerable populations might have low educational and low health literacy levels (Lyles & Sarkar, 2015). They might also have lower levels of digital literacy or less exposure to health technologies (Lyles & Sarkar, 2015). The review findings indicate that

such patients require simple interventions that can be easily adopted by them. The findings also suggest that for effective utilization of telehealth and remote monitoring services, these patients require simplified training that could increase their confidence in using this technology effectively. The review findings have also demonstrated that involving patients' family members in the delivery of telehealth interventions ensures success, especially when it pertains to the vulnerable groups such as racialized minorities and rural populations. This holds true especially for certain cultures, where family is considered an integral part of patient's life and is heavily involved in patient's care (Riegel et al., 2006; Srisuk et al., 2017).

Another important aspect that has been brought up by this review is around health professionals' training to deliver telehealth interventions effectively. Most times, it is taken for granted that health professionals are competent with technical skills involved in telehealth or telemonitoring interventions. However, this might not be the case always, and therefore, a comprehensive training of doctors, nurses, and all other health professionals involved in telehealth/ remote monitoring programs is important for a successful implementation of these interventions (Butzner & Cuffee, 2021).

As much as health professionals' training and preparedness is required, vulnerable patients' access to HF telehealth programs is also essential. This review has highlighted the fact that most telehealth programs are offered at large academic medical centres; whereas, typical heart failure patients, especially the vulnerable groups of HF patients mostly present at primary care clinics in community settings. Therefore, something to be considered is how can we offer telehealth programs for HF patients within primary care clinics in community settings, and what tailoring needs to be done to offer these interventions in a different context with limited resources. These efforts will truly maximize vulnerable patients' access to HF telehealth programs.

Although this review was concerned with telehealth/ remote monitoring interventions; however, some of the telehealth programs did have an in-person component as well, which was deemed really important by the study participants. Also, where there wasn't an opportunity to meet health professionals in-person, the HF patients indicated that they would want to meet their telehealth nurse or physician in-person, at least once. In-person interactions between patients and health professionals serve as rapport building interactions and set the stage for a long-term, positive, patient-provider relationship (Howe et al., 2019).

Just as in-person interactions were deemed important by the participants, the personalization and tailoring of telehealth interventions was also considered to be equally important. This pertains to tailoring these interventions to be culturally relevant for racialized minorities, preferably offering the interventions in their first language that they speak fluently and understand better than English. It is also important to make these interventions more specific to the needs of rural populations, low income groups, and those with lower levels of education / health literacy/ digital literacy, by using simple and easy to understand instructions.

When telemonitoring interventions are performed, an important component of these interventions is the daily monitoring data that comes from HF patients and the prompt decisions that have to be made by health professionals, in case the data shows clinical deterioration or worsening symptoms. The review findings demonstrate that, for prompt action, the data needs to be integrated in the care team's workflow so that the telehealth nurses and physicians know when and how to intervene.

This review has also highlighted some communication-related issues that might interfere with vulnerable patients' utilization of HF telehealth interventions. The review shows that telehealth/ remote monitoring interventions are more effective for racialized minorities if appropriate

translations are used for various telemonitoring equipment and processes, and if medical jargons are avoided. Since many of the HF patients from vulnerable groups have lower levels of health literacy, it is best to use simple language that is understandable and causes less confusion for them.

An important underlying mechanism that was identified through this review is the confidence, sense of security, and comfort with managing one's own HF symptoms that patients experienced with the use of telemonitoring interventions. This realist review explored that this increased level of confidence and comfort reinforced the utilization of telemonitoring interventions for vulnerable groups of HF patients.

### **Strengths**

The foremost strength of this study is its novelty and originality with an intersectionality-based analysis and a rapid realist synthesis performed for the very first time in this area of research.

Another strength of this review is its systematic search in multiple and multidisciplinary databases, which resulted into a comprehensive list of articles from various disciplines such as nursing, medicine, allied health, social sciences etc. Also, the search was not limited by a specific time period, which resulted in studies undertaken at various time points. Additionally, in the search terms, all possible sources of vulnerability were added so as to find studies to any of the vulnerable HF patient populations.

Thirdly, this scoping review maintained the principle of replicability of the search process. A comprehensive search strategy from CINAHL and a PRISMA flow chart have been presented, which would help future researchers conducting reviews on similar topics.

Lastly, the principles of transparency, inter-rater reliability, and accountability were followed throughout the screening process to make it as much robust as possible. Two reviewers screened

each article during the title and abstract screening and while performing the full-text screening. The conflicts were resolved through discussion of rationales for the decisions made.

### **Limitations**

This review is limited by some limitations. First, the search for this review was limited by the articles published in English language; therefore, we might have missed some studies published in other languages. Secondly, the rapid realist synthesis has been performed on the research studies systematically searched through databases, and it does not include grey literature at this point. Realist synthesis approach allows for the inclusion of grey literature along with the research studies (Pawson & Tilley, 1997). However, for this rapid realist synthesis, which was bound by time limitations, it was not possible for us to include grey literature. Though this rapid realist synthesis has generated very important findings that can be readily translated into practice; however, the findings can be further strengthened by including grey literature as part of this realist synthesis. Lastly, the realist synthesis approach also encourages validating the review findings with the key stakeholders, which would eventually lead to a middle-range theory generation (Pawson & Tilley, 1997). Not all realist syntheses include data collection from stakeholders; however, if that could be done, the review findings are validated through primary data. This rapid realist synthesis, limited by logistic barriers related to primary data collection amidst the pandemic, could not include primary data collection from the key stakeholders.

### **Recommendations**

The findings of this review have the potential to significantly improve HF telehealth intervention related clinical practice and research. This review has led to important practice-and-research-based recommendations. Based on the intersectionality-based analysis, the following recommendations are warranted for future research. In the area of HF telehealth for vulnerable

populations, more qualitative, mixed methods, and realist studies are needed, to be able to explore the unique experiences of vulnerable populations and the mechanisms and contexts that make these interventions work for them. Also, more research is needed from contexts and countries other than USA. Moreover, some vulnerable populations of HF patients have not yet been involved in research around HF telehealth interventions, such as, South Asian immigrants, Chinese patients, gender minorities, immigrants and refugees, women with various intersecting social identities, indigenous peoples etc.

This review has also provided some methodological recommendations for future research in the field of HF telehealth interventions for vulnerable patients. This research should be grounded in critical/ intersectionality theory. Also, intersectionality should be applied at all stages of the research process, including analysis. It is also suggested for the researchers to have outcomes specific to measuring health inequities at all levels i.e. individual, interpersonal, organizational, and health systems. Stakeholders, especially the vulnerable groups of HF patients, must be involved at each stage of the research process, to be able to include their voice in all decisions related to the study and to generate user-centred findings.

Some of the practice-based recommendations have been driven out of the realist synthesis. It is recommended to keep telehealth and telemonitoring interventions as much simple as possible for the vulnerable patients who might have lower levels of education, health literacy, and digital literacy. Also, these patients need to be provided simplified training before they utilize HF telehealth/ telemonitoring interventions. Another important recommendation is to include family members as part of the telehealth/ telemonitoring interventions for vulnerable populations, for the patients to receive utmost support in utilizing these interventions. This is especially important for vulnerable patients, for many of whom, family is largely involved in HF care. It is also

recommended to provide training for health professionals who are directly involved in the delivery of telehealth interventions for HF patients. Findings from this review have also led to recommend an essential in-person component as part of the telehealth/ telemonitoring interventions for vulnerable groups of HF patients. Other important recommendations include: personalizing/ tailoring the interventions as per the unique needs of the population of interest, offering HF telehealth interventions at primary care clinics in community settings, incorporating telemonitoring data in health professionals' work flow, fostering trust and acceptance of self-management for vulnerable populations, avoiding jargons, and using appropriate translations during the delivery of HF telehealth/ telemonitoring interventions for racialized minorities.

### **Conclusion**

In conclusion, the findings from this scoping review suggest that the research around HF telehealth interventions for vulnerable populations is not adequately grounded in appropriate philosophical and theoretical underpinning. The principles of intersectionality have been applied mostly to the problem identification and the intervention development and implementation stages, and not so much at the evaluation stage. These are important findings to be considered by HF telehealth researchers; future research with vulnerable populations should be underpinned by the critical/ intersectionality theory, and should apply the principles of intersectionality at all stages of the research process, including evaluation and analysis. This review also urges HF practitioners to apply the principles of intersectionality and health equity in clinical practice, such that the interventions are simple, personalized, involve family members, include an in-person component, include patients' and health professionals' training, and integrate telemonitoring data in care team's work flow. These findings, if fully applied to HF telehealth practice and research, have the potential to significantly improve HF telehealth interventions for

vulnerable patients, making these interventions more specific and relevant to their needs, improving their access to, acceptance and utilization of telehealth interventions, eventually reducing health inequities among these populations.

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## **Chapter 5: Discussion**

### **Overview of Main Findings with Discussion**

Researching a complex intervention such as heart failure (HF) telehealth programs, especially for vulnerable populations, requires a sound philosophical and theoretical basis (Allana et al., 2021b). We explored the potential of critical realism (CR) to underpin intersectionality-based HF telehealth research, and how well it complements the research with vulnerable populations. We also examined the application of intersectionality in designing, implementing, and evaluating HF telehealth programs for vulnerable populations. This intersectionality-based analysis has the potential to inform researchers, practitioners, and policy-makers about the use of intersectionality as an innovative and promising approach to reduce health inequities for vulnerable populations, and highlight the gaps in this area of research.

### **Manuscripts and the Links between Those**

This dissertation is underpinned by the philosophy of CR. Therefore, the first manuscript, which has been published in the *International Journal of Qualitative Methods* (Allana & Clark, 2018), explains in detail the philosophical assumptions of CR and how it relates to HF care research. This paper is the foundation of the entire dissertation as it not only introduces the philosophy of CR, but also explains how and why CR best complements the research around HF disease management interventions. The dissertation then connects the theory of intersectionality with CR that seeks to explain the observable health inequities experienced by vulnerable patients with intersecting social identities, through underlying mechanisms and contextual realities. The second and the third manuscripts set the stage to introduce the concept of intersectionality in the context of HF care and demonstrate the significance of applying intersectionality theory to clinical practice and research in HF care. These manuscripts have been published respectively in

the Journal of Cardiovascular Nursing (Allana et al., 2020) and the Current Opinion in Supportive and Palliative Care (Allana et al., 2021a). These papers are novel and original contributions to the body of literature in the area of HF care, as the concept of intersectionality has been explored in this area of research for the very first time, which seeks to explore the underlying structures of power that generate health inequities in HF care. The fourth manuscript, published in the Canadian Journal of Cardiology Open (Allana et al., 2021b), takes it a step ahead in terms of providing step-by-step practical guidance for cardiovascular researchers to apply intersectionality theory to cardiovascular research. This manuscript provides examples of research questions that can be explored through an intersectionality lens and provides methodological directions. Therefore, this paper is an original contribution towards making cardiovascular health research more focused on the needs of vulnerable populations.

The fifth manuscript (to be submitted to the International Journal of Nursing Studies) presents a comprehensive account of methods and findings from the scoping review, intersectionality-based analysis, and rapid realist synthesis of HF telehealth interventions for vulnerable populations. This manuscript presents important insights around how and why HF telehealth interventions work or not, for the marginalized groups of HF patients. It also suggests recommendations to adopt intersectionality in HF telehealth research in its full essence, based on the intersectionality-based analysis that has been conducted as part of this dissertation. This study is an important addition to the HF telehealth research because this is the very first study that has mapped the existing body of literature around HF telehealth interventions for marginalized populations through a scoping review, explored the extent to which intersectionality has been applied to the studies around HF telehealth interventions, and identified the contexts and mechanisms that make HF telehealth interventions work or not for the

vulnerable/ marginalized groups of HF patients via a rapid realist synthesis. Findings from this dissertation have the potential to significantly improve clinical practice and research in HF telehealth for vulnerable groups of HF patients.

### **Key Insights**

The key insights gained through this dissertation include a lack of application of intersectionality in HF telehealth literature, especially at the evaluation and analysis stage. Also, a lack of qualitative, mixed-methods, and realist research in this area of research has been identified. Another significant finding is a lack of stakeholder participation in HF telehealth intervention research, which indicates that the unique voices of vulnerable patients have not been included in the design and implementation of HF telehealth interventions. The rapid realist synthesis has demonstrated that simple interventions, family involvement in HF telehealth programs, presence of an in-person component, personalization and tailoring of interventions for the specific vulnerable groups, health professionals' training, integration of telemonitoring data in care team's workflow, and appropriate translation of terms are the contextual factors that have the potential to make HF telehealth interventions work for vulnerable groups of HF patients. The key mechanisms include simple interventions with simplified training which lead to confidence in using telehealth/ telemonitoring interventions as well as an increased sense of security and comfort that arises with the use of remote monitoring, and reinforces the continued utilization of these services.

### **Strengths**

The foremost strength of this dissertation is its originality and novelty. This body of work is novel in its approach. Though CR and intersectionality theory both have been used separately in health research since the last two decades; however, these have never been combined to bring

about the underlying structures of power that lead to health inequities for vulnerable populations. Also, the application of CR and intersectionality theory to HF telehealth interventions is an original endeavour. Methodologically, a scoping review, an intersectionality-based analysis, and a rapid realist synthesis have been conducted that have brought about significant findings to make HF telehealth interventions relevant and specific to the needs of vulnerable groups of HF patients. To the best of my knowledge, research in the area of HF telehealth interventions for vulnerable populations has never been mapped via a scoping review. This scoping review has not only mapped the existing body of literature in this area, but has also identified the gaps in this area of research, which have led to concrete recommendations for future research in this very important and timely field of study. Additionally, an intersectionality-based analysis has been performed on the included studies, which has identified the extent to which intersectionality has been applied to these studies. This is the first of its kind analysis which was performed objectively via an intersectionality-informed checklist, and has brought about important recommendations for incorporating intersectionality at various stages of HF telehealth research. These recommendations can also be applied to other similar fields of study. Moreover, this dissertation also includes a rapid realist synthesis rooted in the philosophy of CR, which is also the first in the area of HF telehealth interventions for vulnerable populations. This realist synthesis has helped identify key contexts and mechanisms that make these interventions work or not for vulnerable groups of HF patients. These findings have the potential to make HF telehealth interventions more relevant and specific to the needs of vulnerable groups of HF patients, eventually improving their clinical outcomes and quality of life.

## **Limitations**

This dissertation is limited by a few limitations. First, this dissertation does not involve the collection of primary data, rather it mainly involves the analysis of already published studies. Primary data would have verified and enhanced the findings from the review. The realist synthesis approach also encourages validating the review findings with the key stakeholders, which would eventually lead to a middle-range theory generation (Pawson & Tilley, 1997). Not all realist syntheses include data collection from stakeholders; however, if that could be done, the review findings are validated through primary data. This rapid realist synthesis, limited by logistic barriers related to primary data collection amidst the pandemic, could not include primary data collection from the key stakeholders. Secondly, this dissertation did not include vulnerable patients as patient partners. Research around vulnerable populations should be patient-oriented and should include vulnerable patients throughout the research process, right from the planning of research questions and methods up to knowledge translation. An inability to include patient partners leads to the exclusion of their unique voice in the research process, and could decrease user-centredness of findings. Lastly, the realist review was limited by the inclusion of systematically searched studies through databases, and it does not include grey literature at this point. Though this rapid realist synthesis has generated very important findings that can be readily translated into practice; however, the findings can be further strengthened by including grey literature as part of this realist synthesis.

## **Recommendations**

The findings of this review have the potential to significantly improve HF telehealth intervention related clinical practice and research. This review has led to important practice-and-research-based recommendations. Based on the intersectionality-based analysis, the following

recommendations are warranted for future research. In the area of HF telehealth for vulnerable populations, more qualitative, mixed methods, and realist studies are needed, to be able to explore the unique experiences of vulnerable populations and the mechanisms and contexts that make these interventions work for them. Also, more research is needed from contexts and countries other than USA. Moreover, some vulnerable populations of HF patients have not yet been involved in research around HF telehealth interventions, such as, South Asian immigrants, Chinese patients, gender minorities, immigrants and refugees, women with various intersecting social identities, indigenous peoples etc.

This review has also provided some methodological recommendations for future research in the field of HF telehealth interventions for vulnerable patients. This research should be grounded in critical/ intersectionality theory. Also, intersectionality should be applied at all stages of the research process, including analysis. It is also suggested for the researchers to have outcomes specific to measuring health inequities at all levels i.e. individual, interpersonal, organizational, and health systems. Stakeholders, especially the vulnerable groups of HF patients, must be involved at each stage of the research process, to be able to include their voice in all decisions related to the study and to generate user-centred findings.

Some of the practice-based recommendations have been driven out of the realist synthesis. It is recommended to keep telehealth and telemonitoring interventions as much simple as possible for the vulnerable patients who might have lower levels of education, health literacy, and digital literacy. Also, these patients need to be provided simplified training before they utilize HF telehealth/ telemonitoring interventions. Another important recommendation is to include family members as part of the telehealth/ telemonitoring interventions for vulnerable populations, for the patients to receive utmost support in utilizing these interventions. This is especially important

for vulnerable patients, for many of whom, family is largely involved in HF care. It is also recommended to provide training for health professionals who are directly involved in the delivery of telehealth interventions for HF patients. Findings from this review have also led to recommend an essential in-person component as part of the telehealth/ telemonitoring interventions for vulnerable groups of HF patients. Other important recommendations include: personalizing/ tailoring the interventions as per the unique needs of the population of interest, offering HF telehealth interventions at primary care clinics in community settings, incorporating telemonitoring data in health professionals' work flow, fostering trust and acceptance of self-management for vulnerable populations, avoiding jargons, and using appropriate translations during the delivery of HF telehealth/ telemonitoring interventions for racialized minorities.

### **Conclusion**

In conclusion, the findings from this dissertation suggest that the research around HF telehealth interventions for vulnerable populations is not adequately grounded in appropriate philosophical and theoretical underpinning. The principles of intersectionality have been applied mostly to the problem identification, and the intervention development and implementation stages, and not so much at the evaluation stage. These are important findings to be considered by HF telehealth researchers; future research with vulnerable populations should be underpinned by the critical/ intersectionality theory, and should apply the principles of intersectionality at all stages of the research process, including evaluation and analysis. This review also urges HF practitioners to apply the principles of intersectionality and health equity in clinical practice, such that the interventions are simple, personalized, involve family members, include an in-person component, include patients' and health professionals' training, and integrate telemonitoring data in care team's work flow. These findings, if fully applied to HF telehealth practice and research,

have the potential to significantly improve HF telehealth interventions for vulnerable patients, making these interventions more specific and relevant to their needs, improving their access to, acceptance and utilization of telehealth interventions, eventually reducing health inequities among these populations.

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