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## **Current Opinion in Supportive and Palliative Care**

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

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## **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 fields (3–6), including health (7–10) and epidemiology (11). Although intersectionality can inform clinical practice (12) and research (13), it has yet to become prominent or well-known around either heart failure (14), or indeed, heart disease (11). This paper is a primer to what intersectionality is, and its implications and importance for clinical practice and research into heart failure.

### **What is intersectionality?**

Health outcomes over the life course for black African American women of high-socioeconomic status in the United States 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 sociodemographic 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's 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 Canadian Scottish 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 – the association of not associating with any

gender at all. Yet, despite these growing multiplicities, research into epidemiology, cardiology and public health mostly retains simplistic approaches to a small number of simple social and demographic factors, which are themselves simply analysed, essentially disregarding the intersection of these single factors with the other characteristics of these patients, and the effect of this intersection on the health outcomes (11,15,16).

### **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 (15,17,18).

There are compelling empirical and ethical justifications for intersectional approaches to heart disease (11,14). Firstly, 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 (12,15), disability (19), and emerging social factors entwined with health and social wellbeing, notably geography (19) and gender-identity (20).

Given the centrality of health behaviours and health care 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 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 vent of their binary and singular focus (1). This lack of intersectionality neglects, for example, the negative effects of others factors on women, such as race, disability, or low socioeconomic status (11,15). 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). Heart failure is, similarly, 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, lower personal and economic burdens, and improve hospital readmissions and mortality (22–25).

Heart failure self-care is multi-faceted, requires daily and even hourly attention, and extends across aspects of pharmacological, behavioural and lifestyle managements (22) (Table). Yet, systematic reviews have shown that months and even years after diagnosis, heart failure patients and caregivers lack a basic knowledge of what heart failure is 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 heart failure self-care is strongly influenced by a wide-range of psychosocial and contextual factors (31,32) associated with aspects of 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).

**Table 1: Key domains of HF self-care (AHA Scientific Statement on Self-care) <sup>41</sup>**

<b>Domain</b>	<b>Components</b>
Pharmacological management	
Medication Taking	Adherence / Concordance with prescribed regimen
Behaviour and Lifestyle	
Symptom Monitoring	Do daily weight monitoring Seek help where appropriate from health professionals
Dietary Adherence	Regulate sodium intake (salt in diet)
Fluid Restriction	Regulate fluid intake (usually below 2 litres / day)
Alcohol Restriction	Regulate alcohol intake (1-2 glasses wine / day)
Weight Loss	Avoid being overweight or obese
Exercise	Do moderate physical activity regularly
Smoking Cessation	Stop smoking

Further still, it is clear that daily heart failure self-care is more of a collaborative rather than an individual-endeavour - involving patients and their spouses and family in daily management (27,37–39). 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 (38). 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 as a paradigm was first described well over a decade ago (17,18), and its implications for health and gender, research methodology and population (13,40–42) suggested/proposed/advanced, scant acknowledgement of it has appeared in the cardiovascular disease literature, despite exhortations to using intersectional approaches, for example, in heart failure self-care (14). The literature does refer to the term ‘intersection’, for example, heart failure at the intersection of heart failure and palliative care (38). 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 in heart disease.

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 Indigenous populations in Canada and Australia experience a disproportionate and growing burden of it compared with non-Indigenous Canadians and Australians due to a unique combination of factors such as lower average socioeconomic status, higher levels of alcohol and drug abuse, higher prevalence of mental health issues, lower levels of physical activity, and greater barriers to accessing or receiving health services.

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 England [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 (43).

Another recent study from Spain (44) 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 (44).

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 health care.

### **Recommendations for clinical practice**

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

Intersectionality demands practitioners employ sophisticated approaches to patient care that go beyond a simple cultural awareness. This is captured well by

Wilson and colleagues' (12) call for practitioners to add a deep intersectional dimension to their work : *“...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 this are substantial: intersectional approaches compel clinicians to confront their own, often deeply held, biases (12). Clinicians should question their assumptions and interrogate their interactions with patients for evidence of the presence and influence of intersectionality (12) and move away from approaches to care which emphasize particular risks, such as patient’s sex, exclusively (15) thus avoiding past discriminations.

Where possible 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 patients that proliferate in most text books, trials, and guidelines. To understand, for example, how risk factors for poor heart failure self-care (and associated co-morbidities) may be different due to intersectional risks. To recognize the compounding negative interactions of more neglected risk factors (notably race) with other well recognized ones (notably sex) (11,15).

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 (27,38). 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.

While demanding and complex, the notion of understanding patients' and caregivers' 'different sources of disadvantage' (12) will readily chime with clinicians across all health disciplines, well used to 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).

At the health services level - in chronic care and disease management program design - it is vital to echo 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 far better recognize the presence and influence which intersectional factors have on diagnosis, treatment and disease management of heart failure. While guidelines which acknowledge the distinctive influence of race (15) or patient sex (45) 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 the life (12,16).

## 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 (48), or the influence of race (15). While commendable, in intersectional terms, this recognition of such single factors, is clearly inadequate.

There is a growing awareness of the limitations of approaches to epidemiology and clinical trials which succumb to the pitfalls of social categorization 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 cannot be readily translated to the individual heterogeneity and complexity of the individual 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).

Research studies should be prioritized to identify the nature of intersectional risks associated with adverse care outcomes around health care, 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) on patients' care, experiences and outcomes. Instead, approaches are needed which can explore the multiple presence and interaction of race and ethnicity, social class, income, age, gender identity, geography, and immigration status (1).

The benefits and justification of more incorporation of intersectionality extends beyond social justice and theory (11). Notably, with widespread incorporation into research, intersectionality stands to improve the discriminatory or prognostic accuracy of diagnostic tools, biological or other markers – which will strengthen predictive validity of current and future technologies in individuals (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 convey the full complexities of what it is like, for example, to engage in heart failure self-care as a low-income indigenous (Metis) women living in a deprived downtown community.

## **Summary**

In summary, addressing the full complexity of the ways in which intersectional privilege and disenfranchisement affect heart failure care is not the easy path for research (and researchers), which have historically traded-off clinical complexity for research feasibility. Yet, it is now ethically and clinically key to do so. Acknowledging and incorporating intersectionality in clinical practice and research addresses long standing misalignments between these two worlds, which harm patients and reduce

research quality. Intersectionality offers tantalizing hope for aligning research-based practice with practice-based research.