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Intersectionality in Heart Failure Self-care: Ignorance is not an option

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Heart failure (HF) self-care efforts are shared between patients and lay caregivers, but are often badly done and are poorly understood by patients, caregivers and their health professionals [1,2,3,4]. Yet, the contributions of each remain vital to effective HF self-care.

Reasons for poor HF self-care practices are numerous and complex [1]. Effective HF self-care is difficult– requiring a wide range of sophisticated management activities, from medication management and help-seeking to the promotion of good mental wellbeing [4,5]. Caregiving during HF is also not limited to visible care activities but also includes cognitive and interpersonal skills associated with perception, monitoring, assessment, and communication [2].

Over the last decade, gender and sex differences in aspects of heart disease have been increasingly recognized in a myriad of ways, including via: dedicated guidelines and 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 even 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* [6].

What is intersectionality?

Intersectionality is a paradigm which acknowledges that patient outcomes are rarely shaped by one single factor [7]. Growing out of feminism over the past 20 years, intersectionality challenges how researchers and practitioners understand and research psychological, social, and biological realms [8]. 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, etc.) are examined singularly [8]. Instead, intersectional research studies the nature and / or effects of a *combination* of salient characteristics [7]. Accordingly, a person is not only conceived as being characterized by his or her sex, age, race, socioeconomic or immigration status, but as a combination of various factors- such as middle class older adult male 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.

To date, research into HF self-care utilizing or reflecting intersectionality has been limited in quality and volume. Current studies focus exclusively on single factor analyses. For example, a study exploring HF caregiving around race [9], incorporates no other social factors in the analysis.

While no studies 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 [10]. This study identified that the caregivers' gender, age, education, employment status, ethnicity, and the degree of social connectedness all affected their caregiving role in multiple ways. Also, 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.

Using intersectionality to explore heart failure self-care

Research into heart failure self-care needs intersectional approaches because while this care has strong biological benefits, this care is also fundamentally socially grounded– that is, it occurs in and through a myriad of intersectional 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 [11], knowledge is needed urgently as to how such factors interact in HF self-care.

Intersectional approaches will require researchers to explore current trends further and deeper in more discrete intersectional populations. For example, a current research conveys well that caregiving is both complex and demanding for caregivers [12] in terms of physical, mental and emotional burden. How for example might these challenges differ depending on the sex of the caregiver and their immigration or income status? Further, 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 [12]. 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 [12]. Yet, if the caregivers were affluent males, would these patterns be any different? Intersectionality entices us to ask deeper and more nuanced questions of existing more 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 [8]. Though some researchers argue that qualitative research suits the nature of intersectionality research better; many quantitative tools are also available to explore intersectionality (Bauer, 2014). These include: ANOVA, hierarchical analysis, cross tabulation, logistic regression, and multiple linear regression [13]. 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-methods have a huge potential in intersectionality research as these methods explore interactions of social roles, expectations, needs, and challenges associated with intersectionality in various circumstances [14, 15]. Existing approaches to heart failure self-care in which intersectional approaches could add value, include research into patients and caregivers:

-Experiences of self-care [12, 16]

-Unmet needs [17]

-Characteristics of caregivers of HF patients [18]

-Effects and harms from caregiving [19, 20]

-Emotional well-being, stress, burnout and anxiety [15, 21]

-Knowledge, confidence and skills around heart failure self-care [15]

- Non-adherence to recommended self-care practices [15]

-Social isolation, familial support, and health professional support [15]

-Differential effects from self-care interventions [22]

This intersectional research should incorporate sex, gender, class, ethnicity, and immigration status into sampling [6}.

In conclusion, research using intersectional perspectives are 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 health care practices and policy.

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