

# The Importance of Cultural Awareness in the Management of Heart Failure: A Narrative Review

James M Beattie<sup>1,2</sup>, Teresa Castiello<sup>3,4</sup>, Tiny Jaarsma<sup>5,6</sup>

<sup>1</sup>School of Cardiovascular Medicine and Sciences, King's College London, London, UK; <sup>2</sup>Department of Palliative Care and Rehabilitation, Cicely Saunders Institute, King's College London, London, UK; <sup>3</sup>Department of Cardiology, Croydon University Hospital, London, UK; <sup>4</sup>Department of Cardiovascular Imaging, King's College London, London, UK; <sup>5</sup>Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden; <sup>6</sup>Department of Nursing Science, Julius Center, University Medical Center Utrecht, Utrecht, the Netherlands

Correspondence: James M Beattie, Department of Palliative Care and Rehabilitation, Cicely Saunders Institute, King's College London, Bessemer Road, London, SE5 9PJ, UK, Tel +44 20 7848 5516, Email [jmbeattie@hotmail.com](mailto:jmbeattie@hotmail.com)

**Abstract:** Heart failure is a commonly encountered clinical syndrome arising from a range of etiologic cardiovascular diseases and manifests in a phenotypic spectrum of varying degrees of systolic and diastolic ventricular dysfunction. Those affected by this life-limiting illness are subject to an array of burdensome symptoms, poor quality of life, prognostic uncertainty, and a relatively onerous and increasingly complex treatment regimen. This condition occurs in epidemic proportions worldwide, and given the demographic trend in societal ageing, the prevalence of heart failure is only likely to increase. The marked upturn in international migration has generated other demographic changes in recent years, and it is evident that we are living and working in ever more ethnically and culturally diverse communities. Professionals treating those with heart failure are now dealing with a much more culturally disparate clinical cohort. Given that the heart failure disease trajectory is unique to each individual, these clinicians need to ensure that their proposed treatment options and responses to the inevitable crises intrinsic to this condition are in keeping with the culturally determined values, preferences, and worldviews of these patients and their families. In this narrative review, we describe the importance of cultural awareness across a range of themes relevant to heart failure management and emphasize the centrality of cultural competence as the basis of appropriate care provision.

**Keywords:** migration, heart failure, cultural awareness, cultural competence

## Introduction

Population displacement with internal and external migration is a prominent feature of modern life, these migration flows stemming from a variety of push and pull factors. The United Nations reports that worldwide migration has increased by almost 50% since the millennium, the International Organization for Migration estimating that for 2020, there were 281 million international migrants globally, of whom 26.4 million were refugees.<sup>1</sup> Such forced migration tends to be the consequence of geopolitical drivers including the need to seek refuge from military conflict, persecution, or the loss of socio-economic integrity due to natural disasters, climatic or other environmental changes. Alternatively, some individuals simply want to improve their life chances and economic status, evident in voluntary migration from the relatively impoverished Global South to the more affluent Global North. Other immigration corridors reflect enduring postcolonial ties with territories historically controlled by Western states in Africa, Asia, the Caribbean, and the Americas. This dispersion of people is exemplified in the burgeoning diasporas seen across the nation-states of the World Health Organization (WHO) European region, where international migrants now constitute about 1 in 10 of the resident population, and where cardiovascular disease, often giving rise to heart failure, remains the leading cause of death.<sup>2–4</sup> There has been a recent call to address cardiovascular disease in such migrant populations.<sup>5</sup> Globally, heart failure, across the ejection fraction phenotypic spectrum, affects more than 60 million people.<sup>6</sup> Consequently, with the world on the move and the resulting superdiversity, healthcare professionals dealing with these individuals need to navigate an ever more culturally disparate clinical landscape.

## What is Culture?

Culture...is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society. Edward Burnett Tylor, anthropologist, 1832–1917.

Culture is difficult to define. The broad and all-encompassing early definition, as framed above by Tylor, is certainly elegant, but now seems rather anachronistic and evocative of the era of his fieldwork. Thus, the concept of culture is not set in stone, but dynamic and requires to be given context. A more recent authoritative Lancet Commission report on culture and health emphasized the need to appreciate and accommodate the eclectic mix of traditions and ideologies espoused by those requiring clinical care, and proposed another definition:

The shared, overt and covert understandings that constitute conventions and practices, and the ideas, symbols, and concrete artifacts that sustain conventions and practices and make them meaningful<sup>7</sup>

Culture anchors identity and personhood, providing an intangible backdrop of tacit and explicit mutual understanding shaping the worldview of individuals, families, and communities.

## Race, Ethnicity, and Heart Failure

Race is essentially a social construct largely based on physical characteristics such as skin color, hair texture, facial features, or other anatomical traits, those exhibiting similar distinctive racial features likely sharing a common ancestry or geographic origin.<sup>8</sup> Ethnicity, derived from the Greek “ethnos” meaning nation, is also a social construct. This term is used to define a set of people having a common heritage based on their societal attributes, customs, religious and secular traditions. Ethnicity is rooted in lineage, kinship, and a sense of belonging, different ethnic groups distinguished by their acceptance of deep-seated values determining social norms and behaviors drawn from their shared history. Ethnicity and culture are inextricably linked.

Given that the concepts of race and ethnicity have been socially constructed, there is a growing consensus that such characterizations are devoid of biological salience and should not be used as proxy markers of genomic predisposition to disease.<sup>9</sup> While novel genomic loci have been identified which may influence the prognosis of heart failure or the development of some forms of dilated cardiomyopathy (DCM), in this nascent era of precision medicine, it is important to note that comprehensive genetic testing of those of non-European descent is lacking, and there is a paucity of racial and ethnic diversity in genomics research and biorepositories.<sup>10–13</sup> However, some relevant genetic data have emerged. Compared to their White compatriots, African Americans have a higher prevalence of DCM. A recent genome-wide association study of African Americans with this condition has demonstrated a significant association with a variant intronic locus in the *CACNB4* gene, this gene encoding a member of the beta subunit family of voltage-dependent calcium channel complex proteins necessary for cardiomyocyte contraction.<sup>14</sup> Further, a separate study of DCM found 4 unique variants of the *BAG3* gene occurring almost exclusively in African Americans.<sup>15</sup> This gene is important in the regulation of myocardial cellular function including apoptosis and excitation/contraction coupling. While none of these *BAG3* mutations were causally linked to the initial development of DCM in these individuals, they were associated with a 2-fold increase in the risk of death or heart failure-related hospitalization. Titin, the largest human protein, is an essential component of the cardiac sarcomere. Titin-truncating variants (*TTN*ts) constitute the commonest genetic cause of DCM, and *TTN*ts are more prevalent in women of African ancestry with postpartum cardiomyopathy compared to those of White European descent exhibiting this illness.<sup>16</sup>

We must emphasize that worldwide studies of broader genetic variation show that more than 90% of such disparity occurs within racially or ethnically defined societies rather than between them.<sup>17</sup> There is a relative excess of genetic variability within African populations. This finding is consistent with the “Out of Africa” hypothesis that posits that *Homo sapiens* evolved in one or more ancestral groups in Africa about 150,000 years ago.<sup>18</sup> The dilution of genotypic variation and greater genetic concordance in those of all races or ethnic groups outside that continent reflects the ancient migration flows of early humankind, the assortment of physical characteristics of modern humans across geographic regions likely arising as forms of adaptation to new environments and climates following that dispersal.

Despite being social constructs, the terms race and ethnicity are widely utilized and sometimes conflated in the taxonomy describing the epidemiology of heart failure, and to estimate outcomes for affected populations in the medical and scientific literature. The quality of data relating to heart failure in racial and ethnic minority groups varies markedly, and given the resultant uncertainties, caution is advised in how these data are interpreted and used. Comparing populations aggregated solely on the basis of such differentiation as a means of biological aggregation is to some extent clinically naïve. It is often unclear if classification by racial or ethnic identity is as self-reported by study participants, or if such categorization has been assumed by researchers, and some nominally uniform groups may include several subgroups depending on the collective term used. Guidance on the reporting of race and ethnicity in medical and scientific journals has recently been updated.<sup>19</sup>

While the debate on the relative contributions of nature versus nurture might continue, there are undoubtedly differences in the epidemiology of heart failure between ethnic groups. Susceptibility to the antecedent cardiovascular diseases which result in heart failure and are attributable to modifiable risk factors, varies across world regions,<sup>20</sup> and other aspects such as access to healthcare and socio-economic status may be no less important. The etiologies of heart failure and subsequent outcomes differ depending on the relative economic development of patients' homelands. The Global Congestive Heart Failure Registry is a prospective global cohort study [ClinicalTrials.gov Identifier: NCT03078166] of people diagnosed with heart failure at 257 clinical centers in 40 countries across all 5 continents.<sup>21</sup> A recent analysis of 23,341 patients enrolled between 2016 and 2020 (mean age 63 years; 39% female; 61% with a reduced left ventricular (LV) ejection fraction [HFrEF]) showed that, overall, the most common etiology was ischemic heart disease (IHD) (38%), followed by hypertension (20%), and then idiopathic DCM (15%). However, etiology varied with economic status, with IHD being commonest in high-income countries, with hypertension predominating in low-income countries where rheumatic heart disease, almost eradicated in high-income nation states, was also disproportionately represented. Moreover, this study showed that the proportion of HFrEF patients receiving more complete guideline directed medical therapy (GDMT) was greater in high-income compared to low-income countries, the proportional risk of death within 30 days of a first heart failure-related hospitalization being 3- to 5-fold higher in the latter health economies. Perhaps also related to a lesser degree of socio-economic development, comparatively poor outcomes have also been reported in a review examining the growing problem of heart failure in sub-Saharan Africa.<sup>22</sup> Here up to 75% of patients have a non-IHD etiology, undiagnosed rheumatic heart disease being still relatively common, and some cases secondary to endomyocardial fibrosis, which is specific to equatorial zones. Poor access to diagnostics and effective therapies, particularly relevant to those living in rural communities, means that these heart failure patients present at a younger age and at more advanced stages of the disease. The European Society of Cardiology (ESC) Heart Failure Association (HFA) Atlas describes the heterogeneity of access to comprehensive investigation and treatment for heart failure covering territories in Europe, the Mediterranean, the Middle East, and some countries previously within the Soviet bloc.<sup>23</sup> This dataset confirms a similar relationship between socio-economic status, healthcare resource availability, and outcomes.

Risk-factor profiles relevant to heart failure vary across different ethnic communities and some of these are worthy of comment. According to the World Bank, the South Asian population, principally from the Indian sub-continent, make up about 25% of the world population. While subject to widely accepted modifiable cardiovascular risk factors such as smoking, hypercholesterolemia, and hypertension, South Asians are also exposed to increased cardiometabolic risk from early life compared to their White counterparts. These individuals exhibit an increased prevalence of type 2 diabetes, insulin resistance, and a characteristic central deposition of body fat that mediates altered metabolic activity. Such differential distribution of adipose tissue has been variously attributed to the thrifty genotype or thrifty phenotype hypotheses. The thrifty genotype concept contends that their commonly observed central obesity occurs as a response to ancestral exposure to cycles of feast or famine, easily mobilized central visceral fat providing a potential source of nutrients in a time of need.<sup>24</sup> People would only have experienced famines after the end of the last ice age about 10,000 years ago when many cultural groups transitioned from a nomadic hunter-gatherer existence to one centered on more permanent settlements, their subsistence then increasingly dependent on agriculture. In contrast, the thrifty phenotype hypothesis is based on the theory that exposure to maternal malnutrition in embryonic and early fetal life produces changes in organ development and structure, the resultant typically low birth weight infants having a maternally programmed "memory" that may induce type 2 diabetes and features of the metabolic syndrome in adulthood, inducing premature cardiovascular disease.<sup>25</sup> The theoretically initially adaptive mechanisms described for these thrifty metabolic

hypotheses may become maladaptive in times of plenty, perhaps associated with a move from a rural to an urban environment, or following emigration to a more affluent country and the adoption of a sedentary lifestyle and detrimental dietary habits.

The United States (US) leads the world in terms of net immigration, and most comparative ethnic epidemiologic data have emerged from this country. While the hypotheses described above may have lost some traction in recent years, the MASALA study (Mediators of Atherosclerosis in South Asians Living in America [NCT01207167]) has been underway since 2010.<sup>26</sup> This prospective cohort study of South Asian men and women living in the San Francisco Bay and Greater Chicago metropolitan areas has demonstrated that these individuals exhibit type 2 diabetes, hypertension, hypercholesterolemia, and hypertriglyceridemia at lower body weights compared to those of other ethnicities in the US. Comparing data from MASALA with those from the parallel US-based MESA study (Multi-Ethnic Study of Atherosclerosis [NCT00005487]) confirmed a higher prevalence of type 2 diabetes in the South Asian population compared to other racial groups but suggested that this could not be entirely explained by differences in fat distribution based on analyses of body composition as determined by CT imaging.<sup>27,28</sup> South Asians living in the Indian sub-continent have been shown to present with a myocardial infarction about 10 years earlier than other ethnicities, and an epidemic of heart failure is anticipated.<sup>29,30</sup>

Beyond the South Asian population, recent reviews have described disparities that are evident in the risk factor background, heart failure prevalence, incidence, and outcomes for those from other minority ethnic groups living in the US.<sup>31,32</sup> Black patients more commonly have a non-IHD etiology and present at a younger age compared to other groups, and both Black and Hispanic patients often exhibit demonstrable structural or functional cardiac changes such as LV hypertrophy or systolic dysfunction for some years prior to the clinical presentation with overt heart failure.<sup>33</sup> For men, age-adjusted heart failure mortality is greatest for African Americans, followed by non-Hispanic Whites, American Indians or Alaskan natives, Hispanics, and men from the Asia-Pacific Islands. For women, the highest age-adjusted heart failure-related death rates are seen in African Americans followed by American Indians. Despite improvements in heart failure care, age-standardized rates of heart failure hospitalizations have been static for African American men and women over the past decade, remaining 2.5-fold higher than those for the White population.<sup>32</sup> The reasons behind these persistent disparities are complex. Black Americans exhibit higher rates of obesity, hypertension, and chronic kidney disease compared to other ethnic groups and may be disproportionately affected by social determinants of health, the latter meaning that they more commonly live in relatively segregated deprived neighborhoods with limited access to healthful foods, fewer opportunities to undertake physical activity, and have less access to optimal healthcare.<sup>32</sup>

A recent study based on data from 34,821 socio-economically and ethnically diverse heart failure patients treated between 2012 and 2016 under the Kaiser Permanente integrated care system in Northern California showed that outcomes for heart failure still varied by race or ethnicity despite equal access to care and adjusting for multiple potential confounders.<sup>34</sup> The CHAMP-HF registry collated data on the use of GDMT for 3518 outpatients with chronic HFrEF (LV ejection fraction  $\leq 40\%$ ) between December 2015 and March 2017. These data showed significant shortfalls in the prescription and optimal dosing of angiotensin converting enzyme inhibitors/angiotensin II receptor blockers/angiotensin receptor neprilysin inhibitors,  $\beta$ -blockers, and mineralocorticoid receptor antagonists. However, the quanta of deficits were comparable across all ethnicities.<sup>35</sup> The 2022 American Heart Association (AHA)/American College of Cardiology (ACC)/Heart Failure Society of America guidelines for the treatment of patients with Class C HFrEF propose a Class 1 recommendation for the co-prescription of hydralazine and isosorbide dinitrate in African Americans patients, this therapy promoting the bioavailability of nitric oxide with a reduction in oxidative stress.<sup>36</sup> Some two decades on from the A-HeFT study that showed significant benefits for this patient cohort in improved quality of life and reduced rates of hospitalization and death,<sup>37</sup> this drug combination is still under prescribed in the US, and in the treatment of HFrEF patients of African origin living in Europe.<sup>38,39</sup>

Structural racism may also engender heart failure treatment inequities.<sup>40</sup> Analysis of 2001–2010 data from the National Hospital Ambulatory Medical Care Survey showed that Black people in the US attending emergency departments with dyspnea due to acute heart failure had lower rates of hospital admission compared to White individuals with similar presentations.<sup>41</sup> Even if they were admitted, they were less frequently reviewed and treated by specialist cardiology services.<sup>42,43</sup> Similarly, based on the National Cardiovascular Data Registry, fewer Black or Hispanic HFrEF patients eligible for implantable cardioverter defibrillator (ICD) therapy, or this combined with cardiac

resynchronization therapy (CRT-D), received such devices compared to White patients.<sup>44</sup> Finally, based on data from 377 patients followed for 2 years by 21 ventricular assist device (VAD) service providers across the US and contributing to the Registry Evaluation of Vital Information for VADs in Ambulatory Life (REVIVAL) Study [NCT01369407], there was relative underutilization of durable VADs or transplantation in Black compared to White patients despite similar Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS) profiles and preferences for care.<sup>45</sup>

## Culturally Determined Perception of Disease and Response

Culture significantly determines people's comprehension of the nature and potential implications of their diagnosis with heart failure, their illness-beliefs influencing coping strategies, help-seeking behaviors, the adoption of self-care strategies, and their interaction with healthcare providers. Illness beliefs provide a cognitive framework to explain how patients and families understand the causes, characteristics, and threats posed by disease and how this should be treated.<sup>46</sup> These vary across cultures. The predominant allopathic biomedical approach of contemporary Western medical and nursing practice is based on the perception of disease occurring as a result of various pathophysiologic mechanisms as elucidated by scientific and clinical endeavor. However, this view is not universally accepted, exemplified in the premise put forward in traditional Chinese medicine that illness results from a disequilibrium of opposing yin (cold) and yang (hot) forces, or the concepts underlying Ayurveda, the natural system of medicine that originated in India about three millennia ago and is still widely practiced.<sup>47</sup>

Furthermore, some societies maintain that disease might arise from supernatural interventions such as an act of God, possibly as divine retribution for wrongdoing committed in earlier life.<sup>48</sup> Such causal attribution is consequential as these philosophies may have a bearing on patients' attitudes to illness, to recommended treatment plans, and their expectations of the inevitable end result. Fatalism is more common in those adopting the notion of an underlying metaphysical etiologic process, and some may choose to accept their lot, which may impact their engagement with clinicians or commitment to therapy maintenance.

## Symptom Clusters and Impressions of Symptom Severity

Responses to the lived experience of the manifold burdens of significant heart failure vary across cultures.<sup>49</sup> Heart failure patients are subject to multiple symptoms, the spectrum and intensity of which vary across the illness trajectory, and these symptoms are often refractory to GDMT in the advanced stages of the condition.<sup>50</sup> Symptom clustering involves the co-occurrence of two or more related symptoms that, while consistently associated, may or may not share a common pathophysiologic basis. First defined in the cancer literature, symptom clusters have now been described in a variety of long-term conditions, including heart failure, and in contrast to specific individual symptoms, may better distinguish people with diminishing functional capacity, declining quality of life, a greater need of healthcare resources, and a higher mortality risk.<sup>51</sup> Their exposition may help guide the development of interventions to improve clinical outcomes and benefit health economies.

Studies of patterns of reported symptoms and symptom clusters have demonstrated differences between Western and Eastern heart failure patient cohorts. Data from matched New York Heart Association (NYHA) class II–IV heart failure patients with HFrEF or a preserved ejection fraction (HFpEF) were compared for both inpatients and outpatients living in the US, Asia (China and Taiwan), and Europe (the Netherlands and Sweden), with each geographic region contributing 240 datasets.<sup>52</sup> Identification of symptom clusters was based on analyses of 9 symptoms selected from the 21-item Minnesota Living with Heart Failure Questionnaire (MLHFQ).<sup>53</sup> These included 6 physical symptoms [edema; dyspnea; difficulty walking/climbing stairs; fatigue/increased need to rest; fatigue/low energy; sleep difficulties]; and 3 psychological symptoms [worry; depression; cognitive issues (poor concentration or memory)]. While not identical, there appeared to be a relatively high degree of uniformity in the symptom clustering for these geographically and culturally disparate groups, however a secondary analysis of the US and China/Taiwan data from this study by other researchers suggested a lower level of perceived symptom severity in the Asian cohort, with poorer recognition of potentially important changes in psychological symptoms.<sup>49,54</sup>

Psychological symptoms were prominent in a separate study examining the relationship between symptom clusters and quality of life in an elderly Hong Kong Chinese population with advanced heart failure.<sup>55</sup> These investigators studied



a group of 119 NYHA grade III or IV heart failure patients (mean age  $82.9 \pm 6.5$  years) using Chinese versions of the Edmonton Symptom Assessment Scale (ESAS) and the McGill Quality of Life questionnaire (MQOL), these first developed in Canada in 1991 and 1995, respectively.<sup>56,57</sup> The ESAS includes 9 symptom-related items, and these were unchanged in the Chinese translation. The original 16-item MQOL was validated for the Hong Kong Chinese population (MQOL-HK) but was amended to incorporate 3 additional items pertaining to culturally sensitive components regarding satisfaction with food, sex, and feelings of being respected.<sup>58</sup> Three unique symptom clusters were identified in this study: a distress cluster (breathlessness, anxiety, depression); a decondition cluster (fatigue, drowsiness, nausea, loss of appetite); and a discomfort cluster (pain, generalized discomfort). Each of these symptom clusters was independently associated with adverse effects on quality of life, with the distress cluster predominating. The authors postulated that these symptoms clusters may be different from those seen in the general heart failure population given that this study cohort exhibited more advanced stages of heart failure, and the symptoms evident in the decondition cluster are not uncommon in the later phases of other life-limiting diseases. Similarly, the association of depression and anxiety with dyspnea in the distress cluster may reflect the relative refractoriness of dyspnea in advanced heart failure states, leading to heightened fearfulness. In terms of psychological symptoms, it is important to note that how distress is perceived and expressed are intimately related to culture, evident in the burgeoning transcultural psychiatry literature on so-called “idioms of distress”.<sup>59</sup> Distress is sometimes manifested in medically unexplained somatic symptoms or folk illnesses linked to specific ethnocultural groups, or may vary more broadly depending on the way in which appropriate responses to various stressors or malaise are conceptualized within local societies.

## Culture and Self-Care Behaviors

Heart failure is an ambulatory care-sensitive condition, and self-care is a foundational element of effective management and may improve outcomes.<sup>60</sup> Patients’ perceptions of the potential benefits of suggested therapeutic options often depend on how much these correspond with their culturally determined personal goals and values. The recently updated situation-specific theory of heart failure self-care indicates that cultural factors influence self-care efficacy, and a comprehensive analysis suggests that such factors may variously promote or impede self-care behaviors.<sup>61,62</sup>

A study examining the self-care behaviors of heart failure patients in 15 countries worldwide showed these to be somewhat poor overall.<sup>63</sup> Self-care behaviors regarding medication adherence and exercise were comparable across all countries, but there was wide variation in compliance with advice on weight monitoring, salt restriction, and the uptake of annual flu vaccination where this was available. Such variability may reflect local policies regarding the allocation of educational and clinical resources as well as culturally determined priority setting. Another study specifically explored potential culture-related barriers affecting the self-care of patients with chronic heart failure based on the insight of healthcare providers working with a diverse client group across Israel.<sup>64</sup> Reported attitudinal issues included those motivating the adoption of health promotion strategies such as strict adherence to the use of prescription medication, undertaking increased physical activity, or complying with dietary advice. Relevant to the latter, some patients might choose to conform with the dietary precepts and codes central to their religious or spiritual affiliations, or they may hold that the consumption of some traditional foods is protective.<sup>65</sup> Furthermore, there may be simple practical difficulties in that for some communities, commensality, the communal sharing of meals within families or wider assemblages, represents the normal social convention.

We must also concede that medical and nursing practices are themselves imbued with distinct cultural tenets that tend to align with professionally endorsed standards and protocols, these inclined to be rather formulaic. Indeed, the treatment paradigm of heart failure is largely dominated by a professed optimal model of GDMT, incorporating some policies that may run counter to the treatment preferences of some of the increasingly heterogeneous populations we are privileged to treat.<sup>36,66</sup> Cultural context is not incorporated within such guidelines, but best managing those affected across the gamut of acute and chronic heart failure, particularly those subject to a relatively liminal quality of life in the face of disease progression, requires personalization not only through clinical profiling<sup>67</sup> but also through the lens of their individual cultural perspectives. Patient adjustment to heart failure varies across cultures,<sup>65</sup> and a lack of appreciation of the need to accommodate different perceptions and expectations based on values and belief systems, or scant recognition of the need to adjust working practices to conform with anticipated modes of behavior, may undermine confidence.<sup>68</sup> A recent study

describing the experiences of nurses responsible for the provision of self-care counseling to migrants with heart failure in Sweden showed the challenges they faced due to poor linguistic proficiency and low health literacy in that client group, and emphasized the need to adapt their means of care delivery and to foster trust by ensuring these processes were culturally sensitive.<sup>69</sup>

## Spirituality and Religiosity

Culture determines how people make meaning out of illness and suffering, and their concepts of death and dying.<sup>70,71</sup> People exposed to the reality of human vulnerability and existential distress often avail themselves of the solace provided by their spiritual or religious beliefs. While these terms should not be regarded as synonymous, spirituality and religiosity are also intimately related to culture. This inter-connectedness is unmistakable in the definition of spirituality by the European Association of Palliative Care that evolved from a 2009 consensus conference involving representatives from 27 countries: “The dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred”.<sup>72</sup> There is a positive association between participation in religious or spiritual practices and improved quality of life in those with cardiovascular disease, including heart failure.<sup>73</sup> The importance of spiritual support for those with heart failure has been highlighted, and a variety of tools to assess spiritual distress have been developed.<sup>74,75</sup> However, heart failure patients report that their spiritual needs are often unmet.<sup>76</sup> Health professionals tend to be reluctant to address patients’ spiritual or religious needs, whereas holistic ethnocentric management may afford patients with advanced heart failure the opportunity to voice concerns about matters some perceive as fundamental to their existence. For those actively involved in religious observance, access to specific forms of pastoral support and the rituals delineated by their faith traditions might offer significant consolation. Such support needs to be individualized in accordance with the patients’ and families’ particular ideologies that can be multifaceted. Whether arising from the historical movements of people, the influences of colonization, or more recent migrant resettlement, the ensuing convergence of cultural elements is also evident in the ways some belief systems have evolved into blends of traditional practices and those aligned with the conventions of the major world religions. This process is termed syncretism. Examples include Métis spirituality in Canada, a fusion of Christianity and nature-based folk traditions formed from the intermingling of European settlers and first nation Canadians, and Santería, an Afro-Cuban religion that blends features of Roman Catholicism with traditional Yoruba beliefs, these having transferred with enslaved West Africans. Alevism in Turkey is another example of a syncretic faith, combining elements of Islam and Sufism, along with rudiments of Shamanism. On the other hand, it must be acknowledged that we are living in an increasingly secular age, particularly in the West, and for non-religious heart failure patients, it may be appropriate to provide forms of secular (humanist) pastoral care.<sup>77</sup>

Religiosity and culture are also pertinent to those considering interventions for advanced heart failure. Mechanical circulatory support and heart transplantation may offer some hope of salvation in improved survivorship and wellbeing, but they do impose new sets of risks, burdens, and lifestyle adjustments that may impact the quality of that increased longevity. Some may regard such procedures as meddling and, while still respecting the sanctity of life, might eschew such extraordinary means, preferring to put their trust in a higher power and accept the laws of nature as set by God.<sup>78,79</sup> All the major religions support transplantation, organ donation being regarded as a selfless altruistic act, but particularly associated with Judaism and Islam, views have been mixed with respect to donor organ harvesting based on brain-death criteria rather than the traditional perception of death evident as cessation of cardiorespiratory function.<sup>80</sup> This ambiguity derives from differing interpretations of the definition of death as described in the Halakha (Jewish law) and the Qur’an based on the opinions of rabbinic authorities and Islamic scholars, respectively. However, in Judaism and Islam, saving a life by organ donation is regarded as meritorious and a moral duty, and both in Israel and majority Muslim countries, legislation supports the use of brain-death criteria in facilitating such donation. Further concerns in these countries relate to the process of organ procurement, potentially delaying the burial of heart donor decedents beyond the desired 24-hour timeframe and breaching the physical integrity of the donor’s body. Maintaining intactness of the body is also preferred by those adhering to the teachings of Hinduism, Sikhism, and Buddhism, and this likely contributes to the low rates of organ donation in ethnically Chinese communities that conform to the Confucian emphasis on *xiào shùn* (filial piety).<sup>81</sup>

## Communication and Information Exchange

Effective communication and education are central to the provision of good heart failure care, and require the transference of factual knowledge, professional judgments, and opinions with clarity and purpose. It must be appreciated that this exchange of information is bidirectional. Given the relative complexity of comprehensive heart failure management, and the sometimes-challenging clinical scenarios encountered in day-to-day practice, it is important that the information sender ensures the receiver comprehends the substance of the interchange as best possible, which may involve both verbal and non-verbal communication. The latter includes visual cues such as facial expressions, eye contact, gestures, body language, and spatial distancing, the meanings of which might be rather nuanced and lost to the unknowing casual observer. This interplay can be especially problematic when the respective parties are culturally and linguistically different, a situation that may be associated with higher rates of heart failure-related emergency department attendances and admissions.<sup>82</sup>

Ideally, any discourse between clinicians, patients and their families should be undertaken in the first language of the care recipients, the content calibrated to their level of health literacy. Evidence shows that patient-clinician language concordance improves patient satisfaction and outcomes,<sup>83</sup> but if the patient and clinician do not share a common mother tongue, the use of face-to-face professional interpreters is regarded as the gold standard.<sup>84,85</sup> Qualified medical interpreters offer an assured, neutral, and objective contribution, whereas the use of family members or friends as interlocutors lays open the risk of unrecognized misinterpretation of sometimes difficult conversations, or even the possibility of them covertly incorporating their own views on the proposed management plan. Yet even well-trained experienced interpreters sometimes struggle with the jargon-laden discussions typical of frequently time-constrained heart failure consultations, particularly when the patients appear to have little understanding of the nature of the condition.<sup>86</sup> With regard to patient education, validated multilingual heart failure-related educational material is available through the websites of the ACC ([www.cardiosmart.org](http://www.cardiosmart.org)) and the ESC HFA ([www.heartfailurematters.org](http://www.heartfailurematters.org)).

Elucidation of patients' and families' care preferences based on their cultural reference frames will facilitate appropriately configured treatment plans that resonate with their healthcare-related beliefs and values and engender reciprocal respect and understanding. We need to be mindful that such attitudes are granular and differ within cultural groups, subgroups, and families depending on the degree of acculturation and assimilation within the dominant host population, some individuals adopting behavioral traits and attributes of both the heritage and receiving cultures, effecting various blends of cultural hybridization. We must also appreciate the commonality that attitudes to illness and acceptability of treatment options also vary across a country's ostensibly homogeneous majority population, these no less influenced by the individual's cultural background, personal beliefs, and life experiences.

Dialogue between clinicians, patients, and families requires sensitive handling. Professional guidelines codify the notion of information transfer involving explanation of the etiology, severity, and likely heart failure trajectory, detailed enough to support rational agency, and participation in a multidisciplinary process of valid shared decision-making to ascertain current therapeutic options and formulate future care plans.<sup>66</sup> Similarly, and clearly relevant to those with advanced disease, the ethos of palliative care, now incorporated within GDMT for heart failure,<sup>87</sup> favors open awareness of dying, allowing the sick to come to terms with their situation, attend to any unfinished business, and enable preparations to be put in place to facilitate end-of-life care and better ensure a good death. However, such truth telling as a normative standard has evolved in predominantly Westernized anglophone regions. Conversely, discussing illness, prognosis, and the possibility of impending mortality is anathema to some societies wherein a death taboo exists in the belief that this exposition might portend or hasten that outcome.<sup>88,89</sup> Prompts for broaching these testing and sometimes emotionally charged conversations were included in the recent ESC HFA document,<sup>87</sup> and models of culturally competent communication have been developed which might prove useful in clarifying people's readiness to talk and preferences for disclosure applicable to such consultations.<sup>90</sup>

## Shared Decision-Making and Advance Care Planning

Shared decision-making and advance care planning have come to the fore as central aspects of patient-centered care over the past 20 years or so and represent a marked change from earlier paternalistic praxis. These concepts are enshrined in



the UNESCO Universal Declaration on Bioethics and Human Rights of 2006, article 12 of which stressed the importance of respecting cultural diversity and pluralism. Shared decision-making has been described as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences”.<sup>91</sup> Given the epistemic authority vested in clinicians based on their knowledge and expertise, the sharing of evidence as the basis of decision-making might be regarded as rather asymmetric. However, implicit in the approach of a potentially vulnerable person to the professional for advice, the patient-clinician relationship is based on trust, and the patient can bring their values and preferences to bear in a collaborative course of action to decide appropriate elements of treatment. Trust may also be manifest in other ways. The dual-processing theory of human cognition postulates that decision-making is governed by the integration of two parallel systems of reasoning: a relatively fast, almost automatic, intuitive process, and a slower, more rational analytic process.<sup>92</sup> Ageing is associated with a decline in analytical function, and older people more commonly adopt a non-deliberative common-sense approach to decision-making, particularly if they lack familiarity with the subject or the decisions are being made in a setting to which they are unaccustomed.<sup>93</sup> Since the majority of individuals diagnosed with incident heart failure are  $\geq 65$  years of age, some of these patients might prefer to delegate treatment decisions to trusted professionals working on their behalf.

Shared decision-making is considered an ethical imperative in heart failure management and while there may be variation in the quantum of information some patients choose to receive, consistent with Western bioethical philosophy, a policy of limited or non-disclosure might be deemed as jeopardizing patient autonomy.<sup>94,95</sup> Analogous judgments may arise when members of some ethnocultural groups elect to protect patients from bad news, make treatment decisions collectively through their nuclear family or extended kinship, or choose to involve other biologically unrelated close persons within the patient’s social circle.<sup>96</sup> Moral codes vary globally, and a counterargument may prevail in that such patients and families are, in reality, affirming their autonomy by engaging in group consensus and intergenerational support, routines congruent with their cultural norms and *modi vivendi*. To forestall undermining trust, a discretionary approach is required in avoiding the application of rigid institutional policies, a non-judgmental attitude allowing these individuals to make healthcare decisions according to their cultural orthodoxy.

Heart failure survivorship has improved with effective GDMT, and this progressively ageing patient cohort is now increasingly affected by frailty and other competing life-limiting diseases. This multimorbidity is not well served by single disease guidelines, and this can lead to treatment dilemmas.<sup>97,98</sup> It is important that an open discourse and an iterative method of shared decision-making take place at regular intervals along the heart failure disease trajectory to make certain that established treatment modalities continue to provide net benefit. Similarly, any consideration of potential downstream therapeutic options should be viewed against the background of the patient’s evolving general clinical condition to ascertain that these remain consistent with their preferences for care that may be subject to change. It should be noted that, in 2018, the Centers for Medicare and Medicaid Services in the US mandated utilization of a shared decision-making protocol involving the use of a decision aid for individuals considering ICD therapy for the primary prevention of sudden death. This will be relevant to some patients with HFrEF.

Advance care planning (ACP) is another activity explicitly involving clinician patient communication and shared decision-making, specifically aimed at safeguarding patient autonomy and goal-aligned future care.<sup>99</sup> Undertaken when mental capacity is intact, this voluntary exercise involves the patient, in consultation with their physicians, the wider clinical team, family members, or other close persons, characterizing their choices for prospective care should they be unable to participate in treatment decisions if intellectual capacity later becomes impaired. Thereafter, any treatment plans should comply as much as possible with their documented preferences and values, or where applicable, those as expressed by their previously instructed nominated surrogate decision-maker. Various forms of ACP enactment are available such as advance directives, living wills, advance decisions to refuse treatment, or a durable power of attorney. Context-specific preferences can also be incorporated within such constructs, empowering patients to demarcate ceilings of care to avoid futile burdensome interventions close to the end of life, including their views on cardiopulmonary resuscitation. The scope and legal standing of such instruments are contingent on local legislation, and it should be noted that in some jurisdictions, this includes access to physician-assisted dying. While the focus of ACP has shifted upstream from terminal care, given the conditionality of the benefits of implanted devices, for device-eligible heart failure patients this may be particularly relevant to deactivation of

ICDs, decisions to forgo per protocol replacement of battery-depleted devices in the face of inexorable clinical decline towards the end of life, or the withdrawal of mechanical circulatory support following significant device-related complications. Even though about 40% of heart failure patients develop some degree of cognitive impairment,<sup>100</sup> the use of ACP has not been widely adopted,<sup>101,102</sup> and at times, clinicians must assume responsibility for decision-making in the best interests of the patient. In such circumstances, it is important that health professionals avoid imposing value judgments that may conflict with the cultural perspectives of the patient or their family.

Cultural mores may influence preparedness to engage with ACP. A recent Cochrane Database systematic review recognized that ethnicity and cultural values may affect the awareness and acceptability of ACP for heart failure,<sup>103</sup> and studies show that non-White patients in the US, and immigrants of Asian or Southern European descent in Australia engage less frequently in ACP.<sup>104,105</sup> Various factors may have a bearing on the above observations. Research has shown that people from minority cultural and ethnic backgrounds may distrust the healthcare system in the belief that participating in ACP may deny them potentially beneficial medical interventions,<sup>106</sup> and a cross-cultural study from the Netherlands demonstrated that higher levels of educational attainment and greater religious adherence correlated positively and negatively, respectively, with rates of completion of advance directives.<sup>107</sup> The 8<sup>th</sup> International Conference on ACP took place in Singapore in May 2023, and aligned to this meeting, a special issue of *Z Evid Fortbild Qual Gesundheitswes* was published, which included contributions from 29 countries and regions describing various concepts, frameworks, research, and national practices in connection with ACP.<sup>108</sup> While not specifically focused on heart failure, this publication offers a comprehensive international overview of the principles of ACP in relation to cultural diversity.

## The Clinical Interface and Cultural Competence

Cultural diversity is multi-dimensional and cannot be quantified, but we have to acknowledge that minority ethnic groups living alongside dissimilar majority national populations are often marginalized and rendered vulnerable by a variety of intersectional stressors that moderate their social capital. The WHO defines social determinants of health as “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life”, and a recent AHA Scientific Statement outlined the range of sociocultural factors influencing the wellbeing and outcomes of those with heart failure from disadvantaged populations subject to structural inequality.<sup>109</sup> Exposure to the chronic and fluctuating stresses associated with discrimination, disadvantage, and life events, including migration, has been shown to be associated with elevation of stress hormones and inflammatory markers, this so-called allostatic loading adversely affecting outcomes in heart failure.<sup>110,111</sup>

Beyond the impact of language and informational barriers, sociocultural dissonance may also bring about subtle forms of microaggression or discrimination in patient–clinician interactions. Accepting that the life course, social position, level of educational attainment, and cultural background of such clinicians will often differ markedly from those for whom they care, there is a risk of “othering” in the view that such dissimilarities denote individuals who are essentially alien and inferior.<sup>112</sup> To prevent this, Tervalon and Murray-García’s concept of cultural humility has emerged as a means of improving clinicians’ sensitivity to patients’ and families’ multifaceted needs.<sup>113</sup> This involves healthcare staff recognizing their relative privilege and the resulting power imbalance, critically reflecting on their modes of practice to better discern any latent cross-cultural biases, perhaps rooted in their own cultural milieux, and avoiding any stereotypical assumptions potentially impacting empathetic elaboration of the complex array of support required of each individual.<sup>114</sup> This continuous process of deliberation and self-awareness promotes openness and adaptability, enhancing the skill-set of the professional to deliver culturally congruent care. While in reality it is unrealistic to assume that individual medical and nursing professionals could ever become expert enough to fully understand the nuances peculiar to the range of cultural admixtures encountered in today’s pluralist society, acquisition of the knowledge, skills, and attitudes embodied in the complementary concept of cultural competence provides a utilitarian framework to deliver culturally sensitive care. Since first described about 30 years ago, various definitions of cultural competence have been utilized. In the US, the Health and Human Services Office of Minority Health describes cultural competence as the provision of “effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices”, an obligation long endorsed by the Transcultural Nursing Society.<sup>115</sup> Cultural competence is basic to person-centered care and an assortment of didactic educational, self-directed learning, and

mentoring models have been developed to progress this, these widely used by medical, nursing, ancillary health, and social work professionals, some integrated within compulsory training programs. A number of patient-centered quality indicators have been evaluated as measures of cultural competence, and evidence shows that this knowledge base improves the equity of access and utilization of health services by vulnerable communities.<sup>116,117</sup>

However, we would stress that developing cultural competence is not just the responsibility of individuals providing patient-facing care, but also the remit of those managing cardiovascular healthcare systems and the organizational aspects of heart failure services, which need to be tailored to respect and provide for the sociocultural values of local populations. A recent review of systems-level interventions to improve cultural competence highlighted three principles central to its successful implementation: user engagement in strategic development, organizational readiness, and delivery across multiple sites.<sup>118</sup> Building the required infrastructure for delivering culturally safe healthcare requires the commitment of policymakers, and those tasked with service modelling, system analysis and design, and financial management. In the US, under the auspices of the Office of Minority Health since 2001, the provision of culturally competent healthcare services has been based on national standards for Culturally and Linguistically Appropriate Services (CLAS),<sup>119</sup> these 15 standards being a combination of mandates, guidelines, and recommendations (<https://thinkculturalhealth.hhs.gov/clas>). Standard 1 cites the need to “provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs”. The remaining standards encompass three themes: governance, leadership, and workforce (Standards 2-4); communication and language assistance (Standards 5-8); and engagement, continuous improvement, and accountability (Standards 9-15).

## Conclusion

In this review, we have highlighted subject matter demonstrating the importance of cultural awareness in heart failure management. Given the emerging trends in population movement and the growing prevalence of heart failure in the increasingly diverse societies in which we live and work, we need to ensure that cultural competence is embedded as a standard feature of routine clinical practice. This calls for the development of initiatives to support both professional education and process change. Successful delivery of this essential element of person-centered heart failure care requires meaningful engagement and collaboration between clinicians and a multisectoral group of stakeholders and may entail service redesign to improve equity of access by marginalized groups depending on the configuration of local healthcare systems.

## Disclosure

The authors report no conflicts of interest related to this work.

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