

Culture, ethnicity, and socio-economic status as determinants of the management of patients with advanced heart failure who need palliative care: A clinical consensus statement from the Heart Failure Association (HFA) of the ESC, the ESC Patient Forum, and the European Association of Palliative Care

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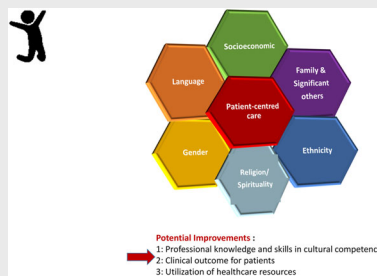
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The delivery of effective healthcare entails the configuration and resourcing of health economies to address the burden of disease, including acute and chronic heart failure, that affects local populations. Increasing migration is leading to more multicultural and ethnically diverse societies worldwide, with migration research suggesting that minority populations are often subject to discrimination, socio-economic disadvantage, and inequity of access to optimal clinical support. Within these contexts, the provision of person-centred care requires medical and nursing staff to be aware of and become adept in navigating the nuances of cultural diversity, and how that can impact some individuals and families entrusted to their care. This paper will examine current evidence, provide practical guidance, and signpost professionals on developing cultural competence within the setting of patients with advanced heart failure who may benefit from palliative care.

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Graphical Abstract



Promoting cultural competence in the management of patients with advanced heart failure

Keywords Culture • Ethnicity • Cultural competency • Advanced heart failure • Palliative care

Introduction

Population movement is a distinctive feature of modern life, the World Health Organization (WHO) noting in 2017 that at least 92 million people living in their European Region were international migrants.¹ An individual's decision to migrate may be determined by an assortment of 'push and pull' factors, such as forced migration secondary to geopolitical drivers, including international or civil war, or voluntary, when they seek to better themselves. Wherever the individual resides, throughout Europe or across the globe, the backdrop of wellbeing and illness, chronic disease epidemiology, and healthcare delivery differs.^{2,3} Despite medical advancements, the prevalence of heart failure (HF), estimated at 64.3 million individuals worldwide,^{4,5} is projected to rise in the coming decades.^{6,7} Many health professionals, including those working in HF, are conscious of the range of ethno-racial diversity within their clinical practice, and question how best to recognize and respond to the culturally determined needs of those in their care. This questioning is relevant to all professionals responsible for the care of individuals across the entire HF disease trajectory. This includes those in primary care dealing with individuals at risk of HF, those offering specialist HF services, and those treating patients with advanced HF. Patients in the latter clinical cohort, the primary focus of this document, are often subject to burdensome symptoms refractory to guideline-directed therapy, an awareness of prognostic uncertainty, and experience existential distress.⁸ This timely paper seeks to raise awareness of the principles of cultural competence, and to provide practical tools and guidance to support clinicians in becoming more culturally competent in the care of their patients with advanced HF, and to better meet their palliative care needs. Reference will be made to other factors including socio-economic status and gender. Given the authorship, we acknowledge that this statement offers a predominantly Western approach to the subject.

Cultural competence for heart failure multidisciplinary team

Cultural competence may be defined as an understanding of how culture affects an individual's beliefs, values and behaviours.⁹ Today, healthcare providers and organizations are expected to provide a person-centred approach to care which requires recognition of the cultural, social, and religious/spiritual preferences of patients and their families. This entails the development of strategies to ascertain and address the bespoke needs of individuals across the cultural spectrum within local populations. A meta-analysis of 19 review articles published between 2000 and 2012 concluded that interventions to increase cultural competence were effective in enhancing the knowledge, skills and attitudes of healthcare providers, leading to clinical benefits for patients/clients through improved access and utilization of healthcare.¹⁰ Indeed cultural competence may improve quality of care and drive national and international initiatives to reduce healthcare inequalities in multicultural societies.¹¹ Relevant to the HF multidisciplinary team, good practice requires that all members achieve an appropriate level of cultural competence, this proficiency being applicable for every clinical encounter.

A growing number of cultural competence self-assessment tools are available. Some of these are in the public domain and free to use online (www.ecald.com/resources/cross-cultural-resources/cross-cultural-resource), others require payment (IAPCC-SV | Transcultural C.A.R.E Associates [transculturalcare.net]) or were developed for specific areas of use – be that for teaching or implementation studies.¹²⁻¹⁴ The proliferation of interest in cultural competence has led to a wide range of pedagogical approaches to teaching and learning, yet there remains a lack of uniformity in the putative domains of key knowledge and skills, as well as the standards and measures indicative of effective implementation.¹⁵

Key concepts

Race and ethnicity are social constructs with limited biological significance, but which can be intimately related to socio-economic status. Race is generally considered a concept describing populations who share similar physical characteristics such as skin colour and facial features. In contrast, ethnicity refers to people with a common descent who hold to similar cultural traditions and values. In this consensus statement we have complied with the recently updated guidance on the reporting of race and ethnicity in medical and science journals.¹⁶ In doing so, we acknowledge that use of the term 'Black' may include people with a mixture of ancestry and heritage. We also concede that for some cohorts included in the cited literature, we cannot ascertain if racial or ethnic groups self-identified as such or were so designated by the researchers involved.

To become more culturally competent healthcare professionals must become self-aware that their own cultural background, determining their interlinked personal morals, attitudes, and beliefs, might introduce bias within their practice. Concepts of cultural awareness, cultural humility, and additional key constructs, alongside their definitions and implications for clinical practice, are outlined in [Table 1](#).^{10,17-33}

Religion and spirituality

Religion and spirituality lie outside the biomedical model of care and are not included in medical and nursing curricula yet may be the bedrock of many patients' lives. For those patients with advanced HF, religion and spirituality may play major roles in enabling them to cope with advanced therapies (such as mechanical circulatory support [MCS] or transplantation), or in bolstering emotional welfare, alleviating health concerns, and improving adherence to treatment.³³

Spirituality appears to be associated with better quality of life; however, evidence is limited on the impact of spirituality on patient care and end-of-life decision-making.³⁴ Recognized and included within the WHO definition of palliative care, patients with chronic illnesses often have their spiritual needs inadequately addressed by healthcare professionals.³⁵ Effective strategies developed and adopted within the specialty of oncology, could inform better integration of spiritual support into the care of patients and families dealing with advanced HF.³⁶ For simplicity, the major world religions can be grouped into three faith strands – Abrahamic, Eastern and Indigenous faiths ([Table 2](#) and online supplementary material).

Heart failure prevalence

The prevalence of HF varies across European countries, ranging from 1.3% in Belgium to 4% in Germany, with similar diversity recorded in North America (range 2.4–3.6%). A lower prevalence was reported in Japan, India, and in some regions of China (0.8%, 0.3% and 1.3%, respectively).³⁷ Such heterogeneity is also within countries, as illustrated by the higher cardiovascular rate of South Asian immigrants compared to other migrant groups living in Europe.³⁸ Furthermore, a survey of >1 million

patients registered for primary care in England, found individuals of Pakistani, Bangladeshi or Arab origin experienced poorer health-related quality of life compared to White British residents.³⁹

Contributing factors

Socio-economic status has been found to have an impact on the prevalence of HF as shown in the United Kingdom (UK), whereby it is 2% in the most deprived areas compared to 1.2% in more affluent communities.⁴⁰ Age-specific trends were also found in Denmark, in that incident rates for HF have declined over the last two decades among individuals aged >50 years, whereas they have increased in the ≤50-year cohort.⁴¹ Gender-specific disparities are also becoming more evident, with a lower incidence of HF with reduced ejection fraction in women, this contrasting with a rising incidence of the preserved ejection fraction phenotype.⁴² Meanwhile, the prevalence of advanced HF, as shown in the Olmsted County cohort study, has increased over time in both sexes, reaching 13.7% of the total HF sample, with a median time of 12 months from the diagnosis of advanced HF to death.⁴³

Interpreting reported health outcomes based on ethnicity alone is complex and flawed, due to heterogeneity within groups, often not explored within studies. In addition, other factors may be contributory. For example, older White men (aged between 55 and 64 years) from Roma or Irish Traveller communities who live in socially deprived circumstances, will develop more comorbidities, have poorer health outcomes and health-related quality of life, compared to other White men of a similar age living in Ireland or the UK.³⁹ Furthermore, of African American women origin living in the United States of America (USA) are three times more likely to die in hospital with peripartum cardiomyopathy, compared to White mothers.^{18,44} The question remains on whether this is primarily due to genetic predispositions, socio-economic status, inequality of access to healthcare, or variation in response to treatment. Indeed, it could be argued that only in rare exceptions can being of a specific ethnic origin, be a valid proxy for genetic risk (online supplementary material, Case Study 1).

Ethnocultural diversity: Heart failure treatment provision and response

Whilst data fail to demonstrate significant differences in access to primary care based on ethnicity, the subjective experience of accessing primary care remains poorest amongst ethnic minority groups.³⁹ This has implications for the screening for risk factors and the identification of structural heart disease which might be aetiologically relevant to the later development of HF. For example, in a study including 497 Black and 8199 non-Black patients diagnosed with hypertension, after adjusting for a number of clinical factors, there was a 130% higher adjusted risk of developing HF in Black participants.^{45,46} This demands public and professional education, and underscores the need to make every clinical interaction count to identify such factors, and better facilitate early diagnosis and treatment.

Table 1 Definition of key concepts

Concept	Meaning	Examples in clinical practice
Culture	The beliefs, values and customs that determine peoples' worldview. These may be expressed in things like diet, clothing, or rituals, or in the form of language, societal structure, or political systems. ¹⁸	During the 9 th month of the Islamic calendar, Muslims fast. Healthcare providers should discuss and collaborate with patients regarding how best to adjust medication and optimize self-care. ¹⁸
Ethnicity	Distinctive shared origins or social backgrounds and traditions of a group of people that are maintained between generations and bring about a sense of identity that may encompass a common language and religion. ¹⁸	Individuals of south Asian or African descent living in the UK have a higher prevalence of heart failure, including peripartum cardiomyopathy. ¹⁹
Race	Socially constructed concept, usually dissociated from biological or genetic traits.	Patients of African origin are more likely to suffer angioedema than people of a different heritage. ²⁰
Cultural awareness	Recognition of one's biases, prejudices and assumptions about individuals who are different. ^{10,21}	Working in partnership with the patient and family so that individual needs and preferences are addressed.
Cultural humility	Integrated part of cultural competence wherein health professionals question their possible assumptions, beliefs, and biases.	Ability to recognize personal limitations to avoid making assumptions about another individual's culture.
Unconscious bias	Bias is a personal judgement or prejudice favouring or rejecting a certain concept, person, or group and is considered to be unfair. When it occurs unintentionally and without an individual's awareness, this is known as unconscious bias. ^{22,23}	Unconscious bias is purported to influence healthcare practitioners' decisions to deem patients of African descent often less suitable for heart transplantation, at least as first-line therapy, than white patients. ²⁴
Migrant	An individual who changes his or her country of usual residence, irrespective of the reason for migration, and independent of their legal status within the host country. ²⁵	An individual who recently changed their country of residence may experience communication and language difficulties. ²⁶
Intersectionality	Complex, cumulative way in which the effects of multiple forms of discrimination combine, overlap, or intersect in the experiences of some marginalized individuals or groups. ²⁷ Aspects are closely connected to the resilience, quality, and equity of health service delivery, and intimately linked to social determinants of health	Relevance to heart failure care provision and outcomes has recently been emphasised. ^{28–30} For example, marital status, gender and employment intersect, so married females more frequently assume a caring role in supporting their sick husbands ³¹
Gender Identity	Non-cisgender individuals choose to identify as a different gender from that biologically assigned at birth. They may be either transgender male or female or non-binary. ³²	Increased risk of cardiovascular events, such as stroke and myocardial infarction in transgender females. ³³

Table 2 Three main strands of religion

Faiths	Religion
Monotheistic or Abrahamic	Judaism, Christianity and Islam.
Eastern	Hinduism, Buddhism, Confucianism, Taoism, Shintoism.
Indigenous folk or archaic	Aboriginal or animist: often blended with another larger faith tradition, a process termed syncretism.

Variation in diagnosis and treatment

In terms of diagnosis, data from the European Society of Cardiology (ESC) Heart Failure Association's (HFA) recently published Atlas-HF revealed large inter-country variations concerning the availability of natriuretic peptide measurement, cardiac magnetic resonance imaging, and cardiopulmonary exercise testing.² For example, natriuretic peptide was unavailable in Kyrgyzstan, but

widely used across Germany. Therefore, those living in low-income countries may be exposed to both an increased incidence of HF, and more limited diagnostic protocols.⁴⁰ Yet treatment disparities exist even in high-income countries with well-developed clinical services. Black Americans and Latinx patients presenting with HF at a Boston emergency department were less likely than the corresponding White cohort to be admitted to a cardiology service.⁴⁷ Also in the USA, based on aggregated data from the National Hospital Ambulatory Medical Care Survey, Black patients presenting to emergency departments with acute HF symptoms were less frequently hospitalized than White patients with similar presentations.⁴⁸

Self-care behaviours

Cultural beliefs and practices can impact patients' self-care behaviours.⁴⁹ In a qualitative study involving 12 healthcare providers from different cultural backgrounds across Israel, shared cultural background, knowledge, and awareness of differences,

positively influenced the self-care of the patients they encountered. Culture-specific factors influencing self-care include maintaining dietary traditions that may run contrary to the recommended diet,⁵⁰ variation in the degree of willingness to undertake self-care, and beliefs conflicting with proposed medical treatment.⁵¹ Therefore, healthcare professionals must be sensitive to how self-care advice might align with cultural beliefs and adapt patient and family education and support accordingly.

Implantable cardioverter-defibrillator implantation

In terms of specific therapies, a study conducted by Mistry *et al.*⁵² found that South Asians patients with HF living in the UK were significantly less likely to receive implantable cardioverter-defibrillators (ICDs), either as primary or secondary prevention, compared to an age-matched co-located White population. Possible barriers were associated with communication (including language), a reluctance to discuss death or possible modes of dying, or administrative limitations leading to poor education affecting treatment acceptance.⁵³ However, given that many of the participants in the Mistry study were not first-generation immigrants, some of the discrepancy may reflect clinician and systemic biases.^{52,54,55} An individual's health beliefs, shaped by education, culture, and spirituality or religious belief, may also contribute to rejection of modern therapies (online supplementary material, Case Study 2).

Ethnicity and socio-economic factors as determinants of heart failure therapy

Importantly, it must be conceded that a recent systematic bibliometric review found that <38% of 414 randomized controlled trials of HF even reported on ethnicity. Among those so reporting, <19% of participants were described by the researchers as people of colour, indigenous or non-White.⁵⁶ Indeed, the underrepresentation of ethnic minorities within clinical trials was recognized more than two decades ago.⁵⁷ While international guidelines tend not to differentiate treatment protocols according to race,⁵⁵ it has been perceived that African Americans are more at risk of angioedema associated with angiotensin-converting enzyme inhibitors than White patients.¹⁹ Therefore, in 2005 the combination of hydralazine hydrochloride and isosorbide dinitrate was specifically approved by the US Food and Drug Administration (FDA) as a possible treatment alternative to angiotensin-converting enzyme inhibitors for such patients with HF and reduced ejection fraction.⁵⁸ Despite this drug combination significantly reducing HF-related mortality in this cohort compared to responses from other ethnic groups, the decision by the FDA was seen as somewhat controversial, with concerns that it undermined efforts to lessen health inequalities.⁵⁹ Interestingly, the HART study (Heart failure Adherence and Retention Trial) found four significant independent predictors of physicians' failure to prescribe evidence-based medication. These factors included comorbidities ($p=0.030$), age ($p=0.016$), New York

Heart Association class III HF ($p=0.004$) and minority status ($p<0.001$).⁶⁰ Additionally, although ethnicity was not described, a study of >44 000 patients within the Swedish HF registry demonstrated that those of female gender or of lower socio-economic status had increased diuretic use, a lack of specialist referral, and lower rates of device therapy, resulting in greater morbidity and mortality risks.⁶¹ Such disparities were addressed in a recent consensus paper from the HFA promoting patient profiling as a means to facilitate the wider implementation of evidence-based therapies.⁶²

Advanced heart failure interventions

Differences in patients' cultural values and beliefs can also impact aspects of advanced HF therapies, particularly policies for MCS and heart transplantation. Strictness of MCS eligibility criteria (especially as destination therapy) may be perceived differently between various socio-cultural groups based on beliefs surrounding the perception of death, and notions of the sanctity versus quality of life in severe chronic illness.⁶³ Such perspectives reflect patients' personal cultural mores.

Similar factors can influence all stages of the heart transplantation process, from the diagnosis of end-stage HF, pre-transplant evaluation, organ allocation, to post-transplant care. Organ donation from cadaveric donors (including heart donation) can be affected by the beliefs of the donor and their family regarding determination of the point of death.⁶⁴ The major cultural and religious traditions differ in their acceptance of the concept of brain death.⁶⁵ Western cultures tend to agree that the presence of irreversible brain damage leading to loss of one's higher executive functions indicates death is inevitable, thereby allowing organ harvesting from brain dead donors.⁶⁶ Attitudes vary across faith traditions, with Hindus uneasy with the above neurological criterion, and people of Jewish Orthodox faith divided between those who agree, and those who believe that death is solely defined by cessation of the heartbeat. Other groups such as Animists are reluctant to even discuss death.⁶⁷ Some Eastern cultures believe that personhood is distributed throughout the body and not solely in the brain, stressing the importance of the physical body remaining whole and intact, thereby potentially rejecting approaches for organ procurement.⁶⁸ However, people assuming this cultural viewpoint, and doubting the validity of the medical criteria determining death, may still favour discontinuation of futile therapy, providing the relevant spiritual or religious rituals can be observed.^{69,70} The manner of decision-making with regard to withdrawal of therapies also varies across cultures, faiths and beliefs, with many preferring to rely on physicians' or collective families' decision processes.⁷¹ Recognizing and accommodating their central cultural and religious beliefs as best possible, may aid negotiation with a potential organ donor and his/her family if such factors are included in the conversation with appropriate sensitivity. The coordinating team should seek training and may need to receive advice from faith and community leaders to best address the cultural perspectives of their local populations, enabling confident, considerate communication that balances potential treatment elements with the values and beliefs

of patients and families (online supplementary material, Case Study 3).

However, organizational prejudices may also influence the perception of transplantation as a useful option for those patients with advanced HF.^{72,73} In a study of approximately 19 000 patients treated by heart transplantation in the USA over a 10-year period, Black Americans showed an increased 1-year postoperative mortality compared to White patients.⁵⁹ There was a tendency for these patients to be treated and followed in centres with higher-than-expected institutional mortality rates. However, the inter-group difference in 1-year mortality persisted and was even greater for Black Americans transplanted at well performing surgical sites. The accompanying editorial suggested that these findings may arise from a complex interplay of biological and intersectional factors and emphasized the need for further research.⁶⁰ A more recent US study has confirmed persisting underutilization of MCS and transplantation in Black patients with similar health preferences to their White counterparts, even when correcting for HF severity, quality of life, and social determinants of health. The authors posit that decision-making for this treatment may be influenced by structural racism, discrimination, and provider bias.⁷⁴ Professionals must acknowledge that socio-cultural minority groups may face such challenges when accessing healthcare and in securing optimal HF therapies. Being culturally competent, and aware of the dissimilarities arising from a combination of biological responses, socio-economic factors, and attitudinal variation, offers the potential to improve diagnosis, therapy, and therefore clinical outcomes in the diverse HF population.

Cultural awareness towards the end of life

Patients from different ethno-cultural groups exhibit a diverse range of ideologies and traditions which affect how best to respond to their palliative care needs. A review by Baker,⁷⁵ published >20 years ago, identified that culture and ethnicity were more likely to determine the provision, access and receipt of palliative care than age, education, socio-economic status or other variables. One such aspect is communication, including family involvement in healthcare discussions and decision-making, treatment choice, and emotional expression at the end of life.^{75,76} As illness progresses many patients, family members and healthcare professionals are reluctant to discuss end-of-life concerns.^{77,78} This is particularly evident in Anglophone and northern European countries where discussing death is often discouraged, this standpoint potentially affecting professional policies on advance care planning (ACP).⁷⁹

Advance care planning and device withdrawal

Cultural factors can also deter patients and family members from considering or making decisions about future care through an advanced directive or other form of ACP. For example, this may complicate decision-making relating to the withdrawal of MCS

if severe device-related complications render this therapy futile, if this is considered more burdensome than beneficial in the face of inexorable progression of HF, or with the development of other life-limiting comorbidities.⁸⁰ Similar cultural variation is noted regarding discussions and decisions on ICD deactivation. A systematic review of willingness to discuss deactivation found wide differences in patient perspectives ranging from just 12% in an Irish cohort compared to 79% in a Dutch population.⁸¹⁻⁸³ In a USA study, Latinx patients and those described generically by the authors as 'Asians' were more likely to prefer family-centred decision-making than other racial or ethnic groups.⁸⁴ Self-reported race was found to be a significant predictor of ACP and treatment decisions even after controlling for socio-demographic factors.⁸⁵ However, for many patients, the lack of any opportunity to discuss ACP was most concerning and described as unsatisfactory and disempowering.⁸⁶

Intensive care support and resuscitation

In a multicentre observational study of >31 000 patients admitted to intensive care units (ICUs) across Europe, regional variations were noted in the use or limitations of aggressive forms of treatment, and the manner of dying.⁸⁷ Withdrawal versus continuing life-sustaining therapy was significantly associated with patient age, acute and chronic diagnoses, number of days in the ICU, and religion. The follow-up Ethicus-2 study, designed to assess whether there had been a change in end-of-life practices in European ICUs between 1999–2000 and 2015–2016, found that of 4248 patients, cardiopulmonary resuscitation was more actively used and withdrawal of therapies less frequent in Southern Europe compared to Central or Northern European countries ($p < 0.01$).⁸⁸ However, some ethnic groups desire more invasive, life-sustaining medical interventions compared to others. For example, in an American study involving 800 individuals from four ethnic groups – European Americans, African Americans, Korean Americans and Mexican Americans –, European Americans were least likely to want life support ($p < 0.001$), whereas Mexican Americans were generally more positive ($p < 0.001$).⁸⁹ Korean Americans were very positive regarding life support but preferred not to participate personally in the associated decision-making ($p = 0.45$), choosing to delegate decisions on continuing life support to family members. African Americans were the most likely to prefer life be preserved at all costs ($p = 0.002$), but suspected treatment allocation was largely based on one's ability to pay.⁸⁹

We recognize that euthanasia and assisted dying are legally sanctioned in some countries and territories and, as in our earlier position paper, we adopt a neutral stance on such issues.⁷⁸ A recent review highlights that cultural attitudes do affect engagement with such policies, but the authors emphasized that some cultural groups have been significantly underrepresented in empirical research to date.⁹⁰

Place of death

The care plan may include measures to achieve the preferred place of death, this having become a proxy for good quality end-of-life

care – greater rates of home deaths within Western paradigms considered the most desirable outcomes. This is illustrated in the general reluctance of some Aboriginal people of Canada to receive aggressive treatment at the end of life in favour of dying at home.^{91,92} However, preferences for home deaths vary across studies, estimates ranging from 43% to 94%.^{93,94} Historically, people wished to die at home within the comfort of their personal space, surrounded by their family, and with easy access to any religious or spiritual rituals.⁹⁵ The preference of a particular place of death depends on many factors and involves parameters such as the ability of the family and close persons to fulfill patients' wishes, access and acceptability to medical or nursing support, as well as economic status.⁹⁶⁻⁹⁸ Some cultures emphasize the moral obligation of children to care for and respect their elders and believe that family members should care for their ill and dying loved ones with unlimited personal interaction.^{99,100} A gendering issue may be relevant to achieving a home death in that men with HF receive disproportionately more care from their spouses. Older females with HF, who are more often widowed, may be devoid of that spousal support.

While most patients with terminal HF still die in acute medical facilities,^{101,102} recent work, also from Canada, suggests that palliative care involvement doubles the likelihood of these patients dying at home.¹⁰³ Despite the high morbidity and mortality rates associated with advanced HF, hospice utilization remains low across Europe, as formal integration of HF and palliative care services is still unusual.¹⁰⁴ If resources do permit, some patients with HF are now favourably inclined to die in hospices, but these patients tend to access such care later in the disease course compared to those with other chronic illnesses.^{76,105} It is further recognized that there is particularly low engagement of patients with HF from ethnic and cultural minority groups with palliative care and hospice services.^{106,107}

People may refer to having a good death when they die at an advanced age,^{108,109} having completed life's tasks and attended to any unfinished business.¹¹⁰⁻¹¹² However, a good death may also be equated to a lack of suffering, perhaps exemplified in a sudden cardiac death. Regardless of cultural background, people approach death with a variety of beliefs, attitudes, superstitions, hopes and fears.¹¹³ A 'peaceful death' is one that is ubiquitously important to all religious communities.⁹⁵

Impact of culture on communication and the role of the family

Communication

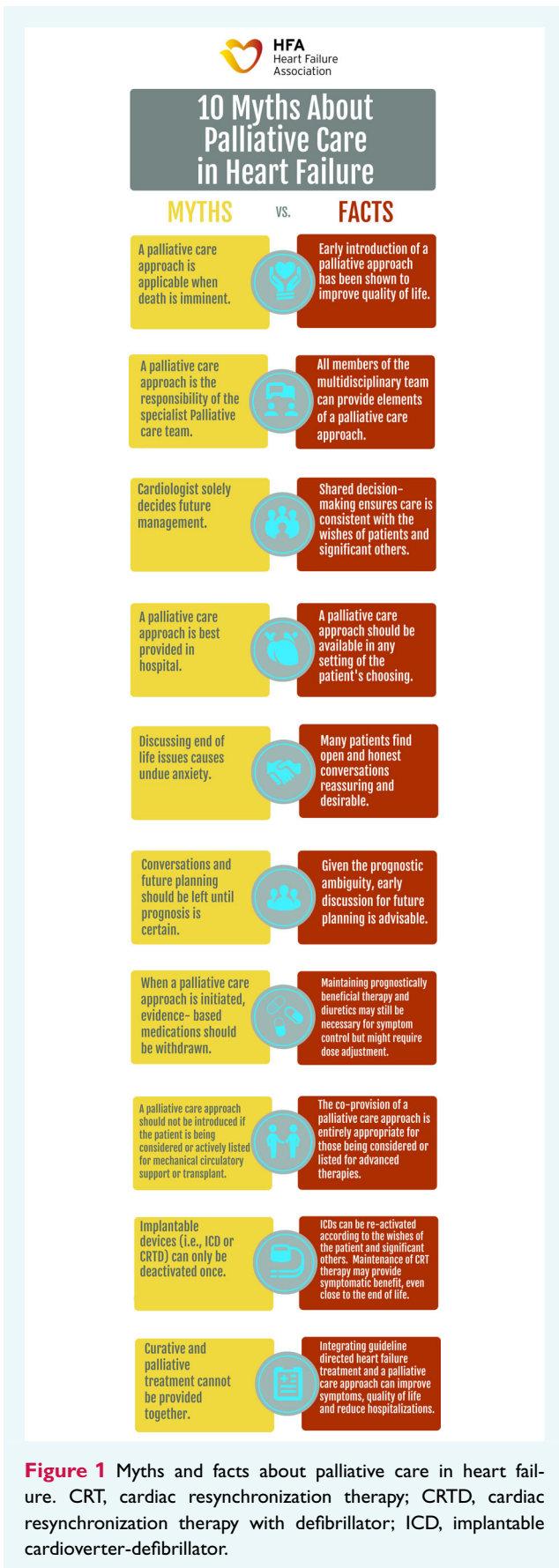
Providing compassionate care requires a combination of person-centred care and cultural sensitivity, and language barriers can add a layer of complexity to the delivery of optimal HF treatment.¹¹⁴ From initial meeting at the point of diagnosis, and through each subsequent consultation, open communication, acknowledging uncertainty in the disease trajectory and prognosis,

and accommodating the values of patients and families, facilitates shared decision-making.^{51,115} The manuscript by Brown *et al.*¹¹⁶ provides a framework of communication strategies to promote cultural competency within nephrology. However, this approach is readily transferable to the care of patients with HF. Such an open discourse is consistent within the precepts of Anglo-American medical ethics, while the norm in other countries may determine that clinical practice is underpinned by family or surrogate decision-making, or the assumption of medical beneficence.¹¹⁷ The HFA has developed an 'aide memoire' for clinical settings to prompt such discussions (Figure 1).

Professionals must be culturally competent to navigate potential conflicts between patients, families and clinical colleagues, particularly when treatment preferences and choices do not align with guideline-directed clinical practice.¹¹⁸ Indeed, a lack of understanding of the beliefs of patients and families can potentially damage the patient-provider relationship. In preserving and bolstering this professional bond, the use of an interpreter may be vital, be that an institutional employee or a bilingual family member. The latter approach is not permitted within the UK. The wishes of the patient should remain paramount in terms of information exchange, and whoever they choose to participate alongside them or as partners in that process. For example, in many European countries, clinicians have a legal and professional obligation to respect patient autonomy and confidentiality. This may be challenged by ethnic groups, such as highlighted in the case studies.

Structure and role of the family

Families are the basic components of all societies, founded on parental duty, mutually supportive relationships, emotional commitment, and oriented to protection and social bonding.¹¹⁹ In recent decades, the structure and organization of the family has been transformed,^{120,121} with the concept of chosen family¹²² adopting a family-centred model of care and healthcare provision.¹²³ The care provided by family members or friends is an important factor throughout the HF trajectory, but particularly so, in the advanced stages of the illness (online supplementary material, Case Study 3). These individuals play significant roles in patient empowerment, coping and self-care, and provide practical, financial, and psychological assistance, individualized to support the patient's day-to-day requirements.^{78,124,125} They also act as an information resource and potentially contribute as surrogate decision-makers. Identifying the role and value placed on family members and/or friends by the patient should determine their degree of involvement in care. Nevertheless, professionals should also be mindful of the caregiver burden, reflecting the physical demands and emotional concerns intrinsic to this supportive role, and the stresses associated with participation in complex decision-making towards the end of life which can complicate bereavement.^{126,127} Consequently, care from culturally competent professionals should be made available to family members, not only from the time of diagnosis and especially during the advanced stages of HF, but also into the period after death.



Conclusion

Treatment for HF has evolved significantly over recent decades as our understanding of the complex pathophysiology underlying this condition has flourished. Despite the extensive implementation of effective guideline-directed therapy, this illness remains burdensome and life-limiting, affecting a predominately aged, multimorbid and increasingly culturally diverse population. However, widespread access to culturally competent care within clinical practice is currently lacking. Improved cultural competence makes a positive impact on patient outcomes, access to healthcare resources, and the delivery of a tailored patient-centred approach to care. This is particularly relevant for health professionals involved with people affected by the advanced and terminal stages of HF, when the predominant requirement is to address their palliative care needs. Assimilation of this skillset will better ensure the provision of bespoke comprehensive care consistent with patients' and families' culturally determined norms and elemental values.

Good clinical practice requires that all healthcare professionals achieve a level of cultural competence which is appropriate for every engagement with a patient. Therefore, we should pause and ask ourselves:

- 1 In your daily practice do you recognize the need for better cultural competence to enable you to address the entire spectrum of care required by your patients?
- 2 Have you access to resources or professionals to support you meeting the specific needs of individual patients/clients from different ethnic groups?
- 3 Have you participated in any formal training programmes related to cultural considerations?

Answering No to any of the questions, highlights the need to update your practice.

Advice for practice, education and policy

Practice

- Review each patient's cultural background and consider consequences on advanced HF treatment and future care whilst appreciating an individual's preferences and beliefs may be at odds with others from the same cultural background.
- Each professional should review their own cultural beliefs and background, and potential consequences on advanced HF treatment and future care.
- Identification of the role of the family members/social network and awareness that roles, constitutions, and patterns may differ for various cultures and ethnic groups.
- Consider patient's preference for linkage with religious/spiritual resources and/or advisors.
- Provisions of culturally appropriate communication tools (interpreter, written resources) to meet the needs of all patients with advanced HF and their families.

- Audit the level of cultural competence among healthcare staff and follow feedback from patients with HF and their family members.

Education

- Incorporation of cultural competence into undergraduate and postgraduate medical and nursing education.
- Annual mandatory training in cultural competency and diversity for all healthcare and administrative staff.

Policy

- Provide equal access to services and facilities for patients with advanced HF, making reasonable individual modifications as necessary to accommodate the needs of different cultures and ethnic groups.
- Encourage maintenance of written cultural competency policy by healthcare providers to ensure diagnostics, treatment and care are delivered in a culturally competent manner to all patients and families affected by HF.

Supplementary Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Conflict of Interest: R.B.: fulltime employee of Astra Zeneca. V.B.: honoraria from AstraZeneca, Bayer, Boehringer Ingelheim, Novartis, Pfizer.T.C.: honoraria from AstraZeneca, Boehringer Ingelheim, Medtronic. J.C.: personal fees from Novartis, AstraZeneca, Boehringer Ingelheim, Pfizer, Bayer. All other authors have nothing to disclose.

References

1. World Health Organization. Report on the health of refugees and migrants in the WHO European region. 2018 Available from: <https://apps.who.int/iris/handle/10665/311347>. Accessed 10 July 2023.
2. Seferović PM, Vardas P, Jankowska EA, Maggioni AP, Timmis A, Milinković I, et al.; National Heart Failure Societies of the ESC member countries. The Heart Failure Association Atlas: Heart failure epidemiology and management statistics 2019. *Eur J Heart Fail* 2021;**23**:906–914. <https://doi.org/10.1002/ejhf.2143>
3. Rosano GMC, Seferovic P, Savarese G, Spolietini I, Lopatin Y, Gustafsson F, et al. Impact analysis of heart failure across European countries: An ESC-HFA position paper. *ESC Heart Fail* 2022;**9**:2767–2778. <https://doi.org/10.1002/ehf2.14076>
4. GBD 2017 Disease and Injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 2018;**392**:1789–1858. [https://doi.org/10.1016/S0140-6736\(18\)32279-7](https://doi.org/10.1016/S0140-6736(18)32279-7)
5. Savarese G, Becher PM, Lund LH, Seferovic P, Rosano GMC, Coats A. Global burden of heart failure: A comprehensive and updated review of epidemiology. *Cardiovasc Res* 2023;**118**:3272–3287. <https://doi.org/10.1093/cvr/cvac013>
6. Ziaean B, Fonarow GC. Epidemiology and aetiology of heart failure. *Nat Rev Cardiol* 2016;**13**:368–378. <https://doi.org/10.1038/nrcardio.2016.25>
7. Heidenreich PA, Albert NM, Allen LA, Bluemke DA, Butler J, Fonarow GC, et al.; American Heart Association Advocacy Coordinating Committee; Council on Arteriosclerosis, Thrombosis and Vascular Biology; Council on Cardiovascular Radiology and Intervention; Council on Clinical Cardiology; Council on Epidemiology and Prevention; Stroke Council. Forecasting the impact of heart failure in the United States: A policy statement from the American Heart Association. *Circ Heart Fail* 2013;**6**:606–619. <https://doi.org/10.1161/HHF.0b013e318291329a>
8. Crespo-Leiro MG, Metra M, Lund LH, Milicic D, Costanzo MR, Filippatos G, et al. Advanced heart failure: A position statement of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2018;**20**:1505–1535. <https://doi.org/10.1002/ejhf.1236>
9. Balcazar FE, Suarez-Balcazar Y, Taylor-Ritzler T. Cultural competence: Development of a conceptual framework. *Disabil Rehabil* 2009;**31**:1153–1160. <https://doi.org/10.1080/09638280902773752>
10. Truong M, Paradies Y, Priest N. Interventions to improve cultural competency in healthcare: A systematic review of reviews. *BMC Health Serv Res* 2014;**14**:99. <https://doi.org/10.1186/1472-6963-14-99>
11. Papadopoulos I, Lazzarino R, Koulouglioti C, Aagard M, Akman Ö, Alpers LM, et al. The importance of being a compassionate leader: The views of nursing and midwifery managers from around the world. *J Transcult Nurs* 2021;**32**:765–777. <https://doi.org/10.1177/10436596211008214>
12. Jeffreys MR, Dogan E. Evaluating cultural competence in the clinical practicum. *Nurs Educ Perspect* 2013;**34**:88–94. <https://doi.org/10.5480/1536-5026-34.2.88>
13. Perng SJ, Watson R. Construct validation of the nurse cultural competence scale: A hierarchy of abilities. *J Clin Nurs* 2012;**21**:1678–1684. <https://doi.org/10.1111/j.1365-2702.2011.03933.x>
14. Suarez-Balcazar Y. Development and validation of the cultural competence assessment instrument: A factorial analysis. *J Rehabil* 2011;**77**:4–13.
15. Horvat L, Horey D, Romios P, Kis-Rigo J. Cultural competence education for health professionals. *Cochrane Database Syst Rev* 2014;CD009405. <https://doi.org/10.1002/14651858.CD009405.pub2>
16. Flanagan A, Frey T, Christiansen SL; AMA Manual of Style Committee. Updated guidance on the reporting of race and ethnicity in medical and science journals. *JAMA* 2021;**326**:621–627. <https://doi.org/10.1001/jama.2021.13304>
17. Alshehri AM, Barner JC, Wong SL, Ibrahim KR, Qureshi S. Perceptions among Muslims regarding fasting, medication use and provider engagement during Ramadan in the United States. *Int J Health Plann Manage* 2021;**36**:945–957. <https://doi.org/10.1002/hpm.3147>
18. Busolo D, Woodgate R. Palliative care experiences of adult cancer patients from ethnocultural groups: A qualitative systematic review protocol. *JBI Database System Rev Implement Rep* 2015;**13**:99–111. <https://doi.org/10.1112/jbisrir-2015-1809>
19. Sliwa K, Bauersachs J, Arany Z, Spracklen TF, Hilfiker-Kleiner D. Peripartum cardiomyopathy: From genetics to management. *Eur Heart J* 2021;**42**:3094–3102. <https://doi.org/10.1093/eurheartj/ehab458>
20. Brown NJ, Ray WA, Snowden M, Griffin MR. Black Americans have an increased rate of angiotensin converting enzyme inhibitor-associated angioedema. *Clin Pharmacol Ther* 1996;**60**:8–13. [https://doi.org/10.1016/S0009-9236\(96\)90161-7](https://doi.org/10.1016/S0009-9236(96)90161-7)
21. Jirwe M, Gerrish K, Keeney S, Emami A. Identifying the core components of cultural competence: Findings from a Delphi study. *J Clin Nurs* 2009;**18**:2622–2634. <https://doi.org/10.1111/j.1365-2702.2008.02734.x>
22. FitzGerald C, Hurst S. Implicit bias in healthcare professionals: A systematic review. *BMC Med Ethics* 2017;**18**:19. <https://doi.org/10.1186/s12910-017-0179-8>
23. Devine PG. Stereotypes and prejudice: Their automatic and controlled components. *J Pers Soc Psychol* 1989;**56**:5–18. <https://doi.org/10.1037/0022-3514.56.1.5>
24. Breathett K, Yee E, Pool N, Hebdon M, Crist JD, Knapp S, et al. Does race influence decision making for advanced heart failure therapies? *J Am Heart Assoc* 2019;**8**:e013592.
25. Lebano A, Hamed S, Bradby H, Gil-Salmerón A, Durá-Ferrandis E, Garcés-Ferrer J, et al. Migrants' and refugees' health status and healthcare in Europe: A scoping literature review. *BMC Public Health* 2020;**20**:1039. <https://doi.org/10.1161/JAHA.119.013592>
26. Gerber K, Maharaj E, Brijnath B, Antoniadis J. End-of-life care for older first-generation migrants: A scoping review. *BMJ Support Palliat Care* 2020;**9**:bmjspcare-2020-002617. <https://doi.org/10.1136/bmjspcare-2020-002617>
27. Dictionary [Internet]. Merriam-Webster INC. 2022 Available from: www.merriam-webster.com
28. White-Williams C, Rossi LP, Bittner VA, Driscoll A, Durant RW, Granger BB, et al.; American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Clinical Cardiology; and Council on Epidemiology and Prevention. Addressing social determinants of health in the care of patients with heart failure: A scientific statement from the American Heart Association. *Circulation* 2020;**141**:e841–e863. <https://doi.org/10.1161/CIR.0000000000000767>
29. Allana S, Ski CF, Thompson DR, Clark AM. Intersectionality and heart failure: What clinicians and researchers should know and do. *Curr Opin Support Palliat Care* 2021;**15**:141–146. <https://doi.org/10.1097/SPC.0000000000000547>

30. Agyemang C, van den Born BJ. Cardiovascular health and disease in migrant populations: A call to action. *Nat Rev Cardiol* 2022;19:1–2. <https://doi.org/10.1038/s41569-021-00644-y>
31. Williams A, Sethi B, Duggleby W, Ploeg J, Markle-Reid M, Peacock S, et al. A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective. *Int J Equity Health* 2016;15:40. <https://doi.org/10.1186/s12939-016-0328-6>
32. Caceres BA, Jackman KB, Edmondson D, Bockting WO. Assessing gender identity differences in cardiovascular disease in US adults: An analysis of data from the 2014-2017 BRFSS. *J Behav Med* 2020;43:329–338. <https://doi.org/10.1007/s10865-019-00102-8>
33. Getahun D, Nash R, Flanders WD, Baird TC, Becerra-Culqui TA, Cromwell L, et al. Cross-sex hormones and acute cardiovascular events in transgender persons: A cohort study. *Ann Intern Med* 2018;169:205–213. <https://doi.org/10.7326/M17-2785>
34. Walton J, St Clair K. εA beacon of lightε. Spirituality in the heart transplant patient. *Crit Care Nurs Clin North Am* 2000;12:87–101. [https://doi.org/10.1016/S0899-5885\(18\)30127-8](https://doi.org/10.1016/S0899-5885(18)30127-8)
35. Fang ML, Sixsmith J, Sinclair S, Horst G. A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review. *BMC Geriatr* 2016;16:107. <https://doi.org/10.1186/s12877-016-0282-6>
36. El Nawawi NM, Balboni MJ, Balboni TA. Palliative care and spiritual care: The crucial role of spiritual care in the care of patients with advanced illness. *Curr Opin Support Palliat Care* 2012;6:269–274. <https://doi.org/10.1097/SPC.0b013e3283530d13>
37. Vallurupalli M, Lauderdale K, Balboni MJ, Phelps AC, Block SD, Ng AK, et al. The role of spirituality and religious coping in the quality of life of patients with advanced cancer receiving palliative radiation therapy. *J Support Oncol* 2012;10:81–87. <https://doi.org/10.1016/j.suponc.2011.09.003>
38. Groenewegen A, Rutten FH, Mosterd A, Hoes AW. Epidemiology of heart failure. *Eur J Heart Fail* 2020;22:1342–1356. <https://doi.org/10.1002/ehf.1858>
39. Cainzos-Achirica M, Fedeli U, Sattar N, Agyemang C, Jennum AK, McEvoy JW, et al. Epidemiology, risk factors, and opportunities for prevention of cardiovascular disease in individuals of South Asian ethnicity living in Europe. *Atherosclerosis* 2019;286:105–113. <https://doi.org/10.1016/j.atherosclerosis.2019.05.014>
40. Watkinson RE, Sutton M, Turner AJ. Ethnic inequalities in health-related quality of life among older adults in England: Secondary analysis of a national cross-sectional survey. *Lancet Public Health* 2021;6:e145–e154. [https://doi.org/10.1016/S2468-2667\(20\)30287-5](https://doi.org/10.1016/S2468-2667(20)30287-5)
41. Conrad N, Judge A, Tran J, Mohseni H, Hedgecott D, Crespiello AP, et al. Temporal trends and patterns in heart failure incidence: A population-based study of 4 million individuals. *Lancet* 2018;391:572–580. [https://doi.org/10.1016/S0140-6736\(17\)32520-5](https://doi.org/10.1016/S0140-6736(17)32520-5)
42. Christiansen MN, Køber L, Weeke P, Vasan RS, Jeppesen JL, Smith JG, et al. Age-specific trends in incidence, mortality, and comorbidities of heart failure in Denmark, 1995 to 2012. *Circulation* 2017;135:1214–1223. <https://doi.org/10.1161/CIRCULATIONAHA.116.025941>
43. Gerber Y, Weston SA, Redfield MM, Chamberlain AM, Manemann SM, Jiang R, et al. A contemporary appraisal of the heart failure epidemic in Olmsted County, Minnesota, 2000 to 2010. *JAMA Intern Med* 2015;175:996–1004. <https://doi.org/10.1001/jamainternmed.2015.0924>
44. Dunlay SM, Roger VL, Killian JM, Weston SA, Schulte PJ, Subramanian AV, et al. Advanced heart failure epidemiology and outcomes: A population-based study. *JACC Heart Fail* 2021;9:722–732. <https://doi.org/10.1016/j.jchf.2021.05.009>
45. Moulig V, Pfeffer TJ, Ricke-Hoch M, Schlothauer S, Koenig T, Schwab J, et al. Long-term follow-up in peripartum cardiomyopathy patients with contemporary treatment: Low mortality, high cardiac recovery, but significant cardiovascular co-morbidities. *Eur J Heart Fail* 2019;21:1534–1542. <https://doi.org/10.1002/ehf.1624>
46. Vasan RS, Musani SK, Matsushita K, Beard W, Obafemi OB, Butler KR, et al. Epidemiology of heart failure stages in middle-aged Black people in the community: Prevalence and prognosis in the atherosclerosis risk in communities study. *J Am Heart Assoc* 2021;10:e016524. <https://doi.org/10.1161/JAHA.120.016524>
47. Okin PM, Kjeldsen SE, Dahlöf B, Devereux RB. Racial differences in incident heart failure during antihypertensive therapy. *Circ Cardiovasc Qual Outcomes* 2011;4:157–164. <https://doi.org/10.1161/CIRCOUTCOMES.110.960112>
48. Eberly LA, Richterman A, Beckett AG, Wispelwey B, Marsh RH, Cleveland Manchanda EC, et al.; Brigham and Women's Internal Medicine Housestaff. Identification of racial inequities in access to specialized inpatient heart failure care at an academic medical center. *Circ Heart Fail* 2019;12:e006214. <https://doi.org/10.1161/CIRCHEARTFAILURE.119.006214>
49. Lo AX, Donnelly JP, Durant RW, Collins SP, Levitan EB, Storrow AB, et al. A national study of U.S. emergency departments: Racial disparities in hospitalizations for heart failure. *Am J Prev Med* 2018;55:S31–S39. <https://doi.org/10.1016/j.amepre.2018.05.020>
50. Jaarsma T, Cameron J, Riegel B, Stromberg A. Factors related to self-care in heart failure patients according to the middle-range theory of self-care of chronic illness: A literature update. *Curr Heart Fail Rep* 2017;14:71–77. <https://doi.org/10.1007/s11897-017-0324-1>
51. McDonagh TA, Metra M, Adamo M, Gardner RS, Baumbach A, Böhm M, et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure: Developed by the Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). With the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur J Heart Fail* 2022;24:4–131. <https://doi.org/10.1002/ehf.2333>
52. Jönsson A, Cewers E, Ben Gal T, Weinstein JM, Strömberg A, Jaarsma T. Perspectives of health care providers on the role of culture in the self-care of patients with chronic heart failure: A qualitative interview study. *Int J Environ Res Public Health* 2020;17:5051. <https://doi.org/10.3390/ijerph17145051>
53. Mistry A, Vali Z, Sidhu B, Budgeon C, Yuyun MF, Pooranachandran V, et al. Disparity in implantable cardioverter defibrillator therapy among minority South Asians in the United Kingdom. *Heart* 2020;106:671–676. <https://doi.org/10.1136/heartjnl-2019-315978>
54. Lala A, Mentz RJ. Overcoming inertia: Announcing double blinded reviews at JCF. *J Card Fail* 2021;27:923–924. <https://doi.org/10.1016/j.cardfail.2021.08.006>
55. National Institute for Health and Care Excellence. Hypertension in adults: Diagnosis and management. NICE guideline [NG136]. 28 August 2019. Accessed 10 July 2023. <https://www.nice.org.uk/guidance/ng136/chapter/Recommendations>
56. Gopal DP, Okoli GN, Rao M. Re-thinking the inclusion of race in British hypertension guidance. *J Hum Hypertens* 2022;36:333–335. <https://doi.org/10.1038/s41371-021-00601-9>
57. Wei S, Le N, Zhu JW, Breathett K, Greene SJ, Mamas MA, et al. Factors associated with racial and ethnic diversity among heart failure trial participants: A systematic bibliometric review. *Circ Heart Fail* 2022;15:e008685. <https://doi.org/10.1161/CIRCHEARTFAILURE.121.008685>
58. Harris Y, Gorelick PB, Samuels P, Bempong I. Why African Americans may not be participating in clinical trials. *J Natl Med Assoc* 1996;88:630–634. PMID:8918067.
59. Taylor AL, Ziesche S, Yancy C, Carson P, D'Agostino R Jr, Ferdinand K, et al.; African-American Heart Failure Trial Investigators. Combination of isosorbide dinitrate and hydralazine in blacks with heart failure. *N Engl J Med* 2004;351:2049–2057. <https://doi.org/10.1056/NEJMoa042934>
60. Bibbins-Domingo K, Fernandez A, BiDiI for heart failure in black patients: Implications of the U.S. Food and Drug Administration approval. *Ann Intern Med* 2007;146:52–56. <https://doi.org/10.7326/0003-4819-146-1-200701020-00009>
61. Calvin JE, Shanbhag S, Avery E, Kane J, Richardson D, Powell L. Adherence to evidence-based guidelines for heart failure in physicians and their patients: Lessons from the Heart Failure Adherence Retention Trial (HART). *Congest Heart Fail* 2012;18:73–78. <https://doi.org/10.1111/j.1751-7133.2011.00263.x>
62. Schrage B, Lund LH, Benson L, Stolfo D, Ohlsson A, Westerling R, et al. Lower socioeconomic status predicts higher mortality and morbidity in patients with heart failure. *Heart* 2021;107:229–236. <https://doi.org/10.1136/heartjnl-2020-317216>
63. Rosano GMC, Moura B, Metra M, Böhm M, Bauersachs J, Ben Gal T, et al. Patient profiling in heart failure for tailoring medical therapy. A consensus document of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2021;23:872–881. <https://doi.org/10.1002/ehf.2206>
64. Asai A, Masaki S, Okita T, Enzo A, Kadooka Y. Matters to address prior to introducing new life support technology in Japan: Three serious ethical concerns related to the use of left ventricular assist devices as destination therapy and suggested policies to deal with them. *BMC Med Ethics* 2018;19:12. <https://doi.org/10.1186/s12910-018-0251-z>
65. Pellegrino ED. Controversies in the Determination of Death. January 2009. https://bioethicsarchive.georgetown.edu/pcbe/reports/death/pellegrino_statement.html Accessed 10 July 2023.
66. Devettere RJ. Neocortical death and human death. *Law Med Health Care* 1990;18:96–104. <https://doi.org/10.1111/j.1748-720x.1990.tb01136.x>
67. A definition of irreversible coma. Report of the ad hoc Committee of the Harvard Medical School to examine the definition of brain death. *JAMA* 1968;205:337–340. <https://doi.org/10.1001/jama.1968.03140320031009>
68. Baeke G, Wils JP, Broeckaert B. Orthodox Jewish perspectives on withholding and withdrawing life-sustaining treatment. *Nurs Ethics* 2011;18:835–846. <https://doi.org/10.1177/0969733011408051>

69. Yang Q, Miller G. East-West differences in perception of brain death. Review of history, current understandings, and directions for future research. *J Bioeth Inq* 2015;**12**:211–225. <https://doi.org/10.1007/s11673-014-9564-x>
70. Hsu CY, O'Connor M, Lee S. Understandings of death and dying for people of Chinese origin. *Death Stud* 2009;**33**:153–174. <https://doi.org/10.1080/07481180802440431>
71. Keown D. Buddhism, brain death, and organ transplantation. *J Buddh Ethics* 2010;**17**:1–36.
72. Evangelical Lutheran-Church in America. 'Patient have a right to refuse unduly burdensome treatments'. A message on end-of-life decisions, 1992 https://download.elca.org/ELCA%20Resource%20Repository/End_Life_DecisionsSM.pdf Accessed 10 July 2023
73. Joyce DL, Conte JV, Russell SD, Joyce LD, Chang DC. Disparities in access to left ventricular assist device therapy. *J Surg Res* 2009;**152**:111–117. <https://doi.org/10.1016/j.jss.2008.02.065>
74. Breathett K, Yee E, Pool N, Hebdon M, Crist JD, Yee RH, et al. Association of gender and race with allocation of advanced heart failure therapies. *JAMA Netw Open* 2020;**3**:e2011044. <https://doi.org/10.1001/jamanetworkopen.2020.11044>
75. Cascino TM, Colvin MM, Lanfear DE, Richards B, Khalatbari S, Mann DL, et al.; REVIVAL Investigators. Racial inequities in access to ventricular assist device and transplant persist after consideration for preferences for care: A report from the REVIVAL study. *Circ Heart Fail* 2023;**16**:e009745. <https://doi.org/10.1161/CIRCHEARTFAILURE.122.009745>
76. Baker ME. Economic, political and ethnic influences on end-of-life decision-making: A decade in review. *J Health Soc Policy* 2002;**14**:27–39. https://doi.org/10.1300/J045v14n03_02
77. Bekelman DB, Nowels CT, Allen LA, Shakar S, Kutner JS, Matlock DD. Outpatient palliative care for chronic heart failure: A case series. *J Palliat Med* 2011;**14**:815–821. <https://doi.org/10.1089/jpm.2010.0508>
78. Marinski G, van Erven L; EHRA Scientific Initiatives Committee. Deactivation of implantable cardioverter-defibrillators at the end of life: Results of the EHRA survey. *Europace* 2010;**12**:1176–1177. <https://doi.org/10.1093/europace/euq272>
79. Hill L, Prager Geller T, Baruah R, Beattie JM, Boyne J, de Stoutz N, et al. Integration of a palliative approach into heart failure care: A European Society of Cardiology Heart Failure Association position paper. *Eur J Heart Fail* 2020;**22**:2327–2339. <https://doi.org/10.1002/ehf.1994>
80. De Gendt C, Bilsen J, Stichele RV, Deliens L. Nursing home policies regarding advance care planning in Flanders, Belgium. *Eur J Public Health* 2010;**20**:189–194. <https://doi.org/10.1093/eurpub/ckp121>
81. Mueller PS, Swetz KM, Freeman MR, Carter KA, Crowley ME, Severson CJ, et al. Ethical analysis of withdrawing ventricular assist device support. *Mayo Clin Proc* 2010;**85**:791–797. <https://doi.org/10.4065/mcp.2010.0113>
82. Groarke J, Beirne A, Buckley U, O'Dwyer E, Sugrue D, Keelan T, et al. Deficiencies in patients' comprehension of implantable cardioverter defibrillator therapy. *Pacing Clin Electrophysiol* 2012;**35**:1097–1102. <https://doi.org/10.1111/j.1540-8159.2012.03448.x>
83. Pedersen SS, Chaiting R, Szili-Torok T, Jordaens L, Theuns DAMJ. Patients' perspective on deactivation of the implantable cardioverter-defibrillator near the end of life. *Am J Cardiol* 2013;**111**:1443–1447. <https://doi.org/10.1016/j.amjcard.2013.01.296>
84. Hill L, McIlpatrick S, Taylor B, Dixon L, Harbinson M, Fitzsimons D. Patients' perception of implantable cardioverter defibrillator deactivation at the end of life. *Palliat Med* 2015;**29**:310–323. <https://doi.org/10.1177/0269216314550374>
85. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist* 2005;**45**:634–641. <https://doi.org/10.1093/geront/45.5.634>
86. Hopp FP, Duffy SA. Racial variations in end-of-life care. *J Am Geriatr Soc* 2000;**48**:658–663. <https://doi.org/10.1111/j.1532-5415.2000.tb04724.x>
87. Ryan M, Farrelly M. Living with an unfixable heart: A qualitative study exploring the experience of living with advanced heart failure. *Eur J Cardiovasc Nurs* 2009;**8**:223–231. <https://doi.org/10.1016/j.ejcnurse.2009.02.005>
88. Sprung CL, Cohen SL, Sjøkvist P, Baras M, Bulow HH, Hovilehto S, et al.; Ethicus Study Group. End-of-life practices in European intensive care units: The Ethicus study. *JAMA* 2003;**290**:790–797. <https://doi.org/10.1001/jama.290.6.790>
89. Sprung CL, Ricou B, Hartog CS, Maia P, Mentzelopoulos SD, Weiss M, et al. Changes in end-of-life practices in European intensive care units from 1999 to 2016. *JAMA* 2019;**322**:1692–1704. <https://doi.org/10.1001/jama.2019.14608>
90. Blackhall LJ, Frank G, Murphy ST, Michel V, Palmer JM, Azen SP. Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med* 1999;**48**:1779–1789. [https://doi.org/10.1016/s0277-9536\(99\)00077-5](https://doi.org/10.1016/s0277-9536(99)00077-5)
91. Karumathil AA, Tripathi R. Culture and attitudes towards euthanasia: An integrative review. *Omega (Westport)* 2022;**86**:688–720. <https://doi.org/10.1177/0030222820984655>
92. Ellerby JH, McKenzie J, McKay S, Gariépy GJ, Kaufert JM. Bioethics for clinicians: 18. Aboriginal cultures. *CMAJ* 2000;**163**:845–850. PMID: 11033715.
93. Kelly L, Minty A. End-of-life issues for aboriginal patients: A literature review. *Can Fam Physician* 2007;**53**:1459–1465. PMID: 17872874.
94. Pritchard RS, Fisher ES, Teno JM, Sharp SM, Reding DJ, Knau WVA, et al. Influence of patient preferences and local health system characteristics on the place of death. SUPPORT investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. *J Am Geriatr Soc* 1998;**46**:1242–1250. <https://doi.org/10.1111/j.1532-5415.1998.tb04540.x>
95. Wilson DM. End-of-life care preferences of Canadian senior citizens with caregiving experience. *J Adv Nurs* 2000;**31**:1416–1421. <https://doi.org/10.1046/j.1365-2648.2000.01456.x>
96. Choudry M, Latif A, Warburton KG. An overview of the spiritual importances of end-of-life care among the five major faiths of the United Kingdom. *Clin Med (Lond)* 2018;**18**:23–31. <https://doi.org/10.7861/clinmedicine.18-1-23>
97. Steinhauer KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;**284**:2476–2482. <https://doi.org/10.1001/jama.284.19.2476>
98. Fried TR, van Doorn C, O'Leary JR, Tinetti ME, Drickamer MA. Older persons' preferences for site of terminal care. *Ann Intern Med* 1999;**131**:109–112. <https://doi.org/10.7326/0003-4819-131-2-199907200-00006>
99. Agar M, Currow DC, Shelby-James TM, Plummer J, Sanderson C, Abernethy AP. Preference for place of care and place of death in palliative care: Are these different questions? *Palliat Med* 2008;**22**:787–795. <https://doi.org/10.1177/0269216308092827>
100. Johnson T, Walton S Jr, Levine S, Fister E, Baron A, O'Mahony S. Racial and ethnic disparity in palliative care and hospice use. *Am J Manag Care* 2020;**26**:e36–e40. <https://doi.org/10.37765/ajmc.2020.42399>
101. Saunders C. The philosophy of terminal cancer care. *Ann Acad Med Singapore* 1987;**16**:151–154. PMID: 3592584.
102. Sudore RL, Fried TR. Redefining the e planning in advance care planning: Preparing for end-of-life decision making. *Ann Intern Med* 2010;**153**:256–261. <https://doi.org/10.7326/0003-4819-153-4-201008170-00008>
103. Enguidanos SM, Cherin D, Brumley R. Home-based palliative care study: Site of death, and costs of medical care for patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer. *J Soc Work End Life Palliat Care* 2005;**1**:37–56. https://doi.org/10.1300/J045v01n03_04
104. Quinn KL, Hsu AT, Smith G, Stall N, Detsky AS, Kavalieratos D, et al. Association between palliative care and death at home in adults with heart failure. *J Am Heart Assoc* 2020;**9**:e013844. <https://doi.org/10.1161/JAHA.119.013844>
105. Cheung WY, Schaefer K, May CW, Glynn RJ, Curtis LH, Stevenson LW, et al. Enrollment and events of hospice patients with heart failure vs. cancer. *J Pain Symptom Manage* 2013;**45**:552–560. <https://doi.org/10.1016/j.jpainsymman.2012.03.006>
106. Mayeda DP, Ward KT. Methods for overcoming barriers in palliative care for ethnic/racial minorities: A systematic review. *Palliat Support Care* 2019;**17**:697–706. <https://doi.org/10.1017/S1478951519000403>
107. Unroe KT, Greiner MA, Hernandez AF, Whellan DJ, Kaul P, Schulman KA, et al. Resource use in the last 6 months of life among Medicare beneficiaries with heart failure, 2000–2007. *Arch Intern Med* 2011;**171**:196–203. <https://doi.org/10.1001/archinternmed.2010.371>
108. Hinton J. *Dying*. London: Penguin; 1967.
109. Kearsal M. *Dying: A sociology of death and dying*. New York: Oxford University Press; 1989.
110. Nimocks MW, Connell JR. Communication and the terminally ill: A theoretical model. *Death Stud* 1987;**11**:323–344. <https://doi.org/10.1080/07481188708252198>
111. Lundin RW, Maslow, Abraham (1908–1970). *Psychol Today* 1970;**4**:16 <https://doi.org/10.1002/9780470479216.corpsy0528>
112. Shneidman E. *Deaths of man*. Bath: Pitman; 1973.
113. Shneidman E. *Voices of man*. New York: Harper and Row; 1980.
114. Robinson J, Moeke-Maxell T, Parr J, Slark J, Black S, Williams L, et al. Optimising compassionate nursing care at the end of life in hospital settings. *J Clin Nurs* 2020;**29**:1788–1796. <https://doi.org/10.1111/jocn.15050>
115. Greene-Moton E, Minkler M. Cultural competence or cultural humility? Moving beyond the debate. *Health Promot Pract* 2020;**21**:142–145. <https://doi.org/10.1177/1524839919884912>
116. Brown EA, Bekker HL, Davison SN, Koffman J, Schell JO. Supportive care: Communication strategies to improve cultural competence in shared decision making. *Clin J Am Soc Nephrol* 2016;**11**:1902–1908. <https://doi.org/10.2215/CJN.13661215>
117. Davison SN, Jassal SV. Supportive care: Integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clin J Am Soc Nephrol* 2016;**11**:1882–1891. <https://doi.org/10.2215/CJN.01050116>

118. Teal CR, Street RL. Critical elements of culturally competent communication in the medical encounter: A review and model. *Soc Sci Med* 2009;**68**:533–543. <https://doi.org/10.1016/j.socscimed.2008.10.015>
119. Itao K, Kaneko K. Evolution of family systems and resultant socio-economic structures. *Humanit Soc Sci Commun* 2021;**8**:243 <https://doi.org/10.1057/s41599-021-00919-2>.
120. Solange Fátima Geraldo da Costa, Regina Célia de Oliveira, Gicely Regina Sobral da Silva Monteiro, Maria Andréa Fernandes, Ana Aline Lacet Zaccara, Gilvânia Smith da Nóbrega Morais, Patrícia Serpa de Souza Batista, Fátima Maria da Silva Abrão. Family structure assessment of patients in palliative home care. *International Archives of Medicine [Internet]* 2016;**9**: 230. <https://doi.org/10.3823/2101>
121. Walrond-Skinner S. *Developments in family therapy (psychology revivals): Theories and applications since 1948*. London: Routledge; 2014.
122. Jackson Levin N, Kattari SK, Piellusch EK, Watson E. εWe Just Take Care of Each Other: Navigating 'Chosen Family' in the context of health, illness, and the mutual provision of care amongst queer and transgender young adults. *Int J Environ Res Public Health* 2020;**17**:7346. <https://doi.org/10.3390/ijerph17197346>
123. Kokorelias KM, Gignac MAM, Naglie G, Cameron JL. Towards a universal model of family centered care: A scoping review. *BMC Health Serv Res* 2019;**19**:564. <https://doi.org/10.1186/s12913-019-4394-5>
124. Kitko L, McIvannan CK, Bidwell JT, Dionne-Odom JN, Dunlay SM, Lewis LM, et al.; American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Quality of Care and Outcomes Research; Council on Clinical Cardiology; and Council on Lifestyle and Cardiometabolic Health. Family caregiving for individuals with heart failure: A scientific statement from the American Heart Association. *Circulation* 2020;**141**:e864–e878. <https://doi.org/10.1161/CIR.0000000000000768>
125. Rempel GR, Neufeld A, Kushner KE. Interactive use of genograms and ecomaps in family caregiving research. *J Fam Nurs* 2007;**13**:403–419. <https://doi.org/10.1177/1074840707307917>
126. Strömberg A, Bonner N, Grant L, Bennett B, Chung ML, Jaarsma T, et al. Psychometric validation of the Heart Failure Caregiver Questionnaire (HF-CQ®). *Patient* 2017;**10**:579–592. <https://doi.org/10.1007/s40271-017-0228-x>
127. Ferrell BR, Coyle N. *Social aspects of care*. London: Oxford University Press; 2015. <https://doi.org/10.1093/med/9780190244132.001.0001/med-9780190244132>