



# Providing palliative care for cardiovascular disease from a perspective of sociocultural diversity: a global view

Patricia M. Davidson<sup>a,b</sup>, Jane L. Phillips<sup>a,b</sup>, Cheryl Dennison-Himmelfarb<sup>a,b</sup>, Sandra C. Thompson<sup>c</sup>, Tim Lockett<sup>b</sup>, and David C. Currow<sup>d</sup>

## Purpose of review

This article discusses the available information on providing palliative care for cardiovascular disease (CVD) for individuals from culturally and linguistically diverse populations, and argues the need for cultural competence and awareness of healthcare providers.

## Recent findings

The burden of CVD is increasing globally and access to palliative care for individuals and populations is inconsistent and largely driven by policy, funding models, center-based expertise and local resources. Culture is an important social determinant of health and moderates health outcomes across the life trajectory. Along with approachability, availability, accommodation, affordability and appropriateness, culture moderates access to services. Health disparities and inequity of access underscore the importance of ensuring services meet the needs of diverse populations and that care is provided by individuals who are culturally competent. In death and dying, the vulnerability of individuals, families and communities is most pronounced. Using a social-ecological model as an organising framework, we consider the evidence from the literature in regard to the interaction between the individual, interpersonal relationships, community and society in promoting access to individuals with cardiovascular disease.

## Summary

This review highlights the need for considering individual, provider and system factors to tailor and target healthcare services to the needs of culturally diverse populations. Beyond translation of materials, there is a need to understand the cultural dimensions influencing health-seeking behaviors and acceptance of palliative care and ensuring the cultural competence of health professionals in both primary and specialist palliative care.

## Keywords

cardiovascular, cultural competence, culture, palliative care, social ecological model

## BURDEN OF CARDIOVASCULAR DISEASE

Cardiovascular disease (CVD) is not only the number one cause of death globally but is also responsible for considerable suffering and disability. An estimated 17.5 million people died from CVD in 2012, representing 31% of all global deaths. Of these deaths, an estimated 7.4 million were due to coronary heart disease and 6.7 million were due to stroke [1]. Heart failure is a major source of morbidity and disability and the final common pathway for many cardiovascular conditions. Heart failure is the most common reason that patients with advanced heart disease require palliative care [2]. More than 5 million Americans, 15 million Europeans and 350 000 Australians have a diagnosis of heart

failure [3–5]. Over three-quarters of CVD deaths take place in low- and middle-income countries, signaling the need to develop policies and workforce

<sup>a</sup>Johns Hopkins University School of Nursing, Baltimore, Maryland, USA,

<sup>b</sup>Centre for Cardiovascular and Chronic Care Faculty of Health, University of Technology Sydney, Ultimo, New South Wales, <sup>c</sup>Western Australia Centre for Rural Health, University of Western Australia, Crawley-Nedlands, Western Australia and <sup>d</sup>Palliative and Supportive Services, Flinders University, Adelaide, South Australia

Correspondence to Patricia M. Davidson, PhD, MEd, RN, FAAN, Dean and Professor, Johns Hopkins School of Nursing, 525N. Wolfe Street, Baltimore, MD 21205, USA. Tel: +1 410 955 7544; fax: +1 410 955 4890; e-mail: pdavidson@jhu.edu

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## KEY POINTS

- Cardiovascular disease is a major source of death and disability globally.
- Chronic heart failure is often a terminal pathway for many cardiovascular conditions.
- Living and dying with a life limiting illness is shaped by social and cultural perspectives.
- Considering social determinants of health and integrating socio-cultural factors is critical in planning accessible and appropriate palliative care.

capacity to reduce suffering and meet the needs of individuals and their families [1]. Whether deaths from CVD are sudden and premature or expected and prolonged, there is an important place for palliative care to decrease suffering for individuals and their families. Considering sociocultural factors beyond the individual, within a broader ecological context, requires consideration of a range of dynamic and interactive factors [6]. A constellation of symptoms, including breathlessness and gastrointestinal symptoms, prompts presentation to the emergency department and admission to the hospital in the advanced stage of CVD [7–9]. Not only do many of these admissions fail to address symptom burdens but also necessitate that individuals die in acute care settings often receiving futile treatments that are distressing to individuals, their family members and health professionals alike [10].

## PALLIATIVE CARE AND CULTURE

Originating from alleviating the suffering of cancer, contemporary palliative care has emerged as an evidence-based, multidisciplinary approach to care for individuals and their families living with serious, life-limiting illnesses [11]. Increasingly, the importance of palliative care for both malignant and nonmalignant conditions is recognized but access is not consistent either across patient populations or geographical boundaries [12]. In order to improve health outcomes and to address inequities, it is important to consider access from the perspectives of the healthcare system, provider and patient levels [13].

Cultural diversity and pluralism are the hallmarks of most contemporary societies, with both forced and voluntary migration having important implications for health services and outcomes [14–16]. Individuals from culturally and linguistically diverse groups are most vulnerable to marginalization because of language barriers and

socioeconomic factors and, as a consequence, are less likely to access services across the lifespan [17,18]. A range of service characteristics influences accessibility including approachability, availability, accommodation, affordability and appropriateness [19]. These factors address not just cost and geographical proximity but also how the characteristics of the health service fit with the users' attitudes, values and beliefs. The complexity of factors driving access also emphasizes the need to accommodate cultural beliefs at the level of the individual, healthcare provider and society. Service characteristics further interact with an individual's beliefs, health literacy, health-seeking behaviors, culture and language and may influence not only healthcare access but also satisfaction [20]. The interplay between the health system, service and patient characteristics means that access to healthcare will require multidimensional consideration both of individual, provider and policy issues.

The core palliative care capabilities that every health professional (nursing, allied health and medical) requires to better support patients and their families at the end of life [21] are termed as palliative approach. It also requires that health professionals' recognize when people with more complex needs should be referred to specialist palliative care services [22]. Consideration of ethnic and cultural issues poses a challenge for palliative care internationally [23]. Palliative care as a philosophy and service model is not always readily embraced. Confronting mortality is a taboo across many cultures and commonly not discussed which can make providing palliative care challenging [24]. Death and dying are highly ritualized in many cultural groups and require specific consideration in palliative care [25]. For historical reasons, there may also be skepticism about palliative care among many minority groups, such as African-Americans and Australian Aboriginals and Torres Strait Islander people, who may be suspicious that withdrawing and withholding treatment is related to reducing costs rather than focusing on improving individual well-being [26,27]. Particularly, in indigenous populations, there is a critical importance to engage community leaders in developing palliative care services [28,29].

Philosophically, palliative care embraces the physical, social, psychological and spiritual dimensions of care. It is often the sentinel events in life, such as birth and death, where sociocultural factors are most pronounced and requires the astute attention of healthcare providers. Sociocultural dimensions of care refer to the knowledge, attitudes, beliefs, customs, practices and behaviors that exists within a specific population [30]. These factors are

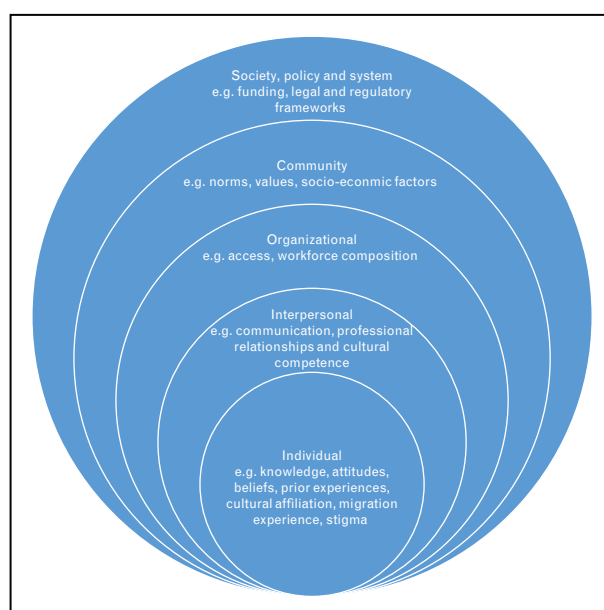
also moderated by the social, political and economic factors influencing healthcare delivery and policy and financing models are of a great significance for the delivery of palliative care. Increasingly, the need to consider culture within the context of palliative care has been recognized and creates an important agenda for the quality of care [31].

Culture is the backdrop against which to consider the needs of individuals, families and communities and can be a powerful force for engagement and understanding, however, it can also fuel stereotyping and prejudice [32,33]. Sociocultural approaches to considering palliative care can sometimes be perceived as superficial by focusing on behaviors such as rituals surrounding death [34]. Although it is important to consider rituals, spiritual and religious needs, standardized policies and procedures risk stereotyping individuals and groups, although general practices can also serve as a valuable basis for ensuring culturally competent care [35]. Cultural competence refers to the behaviors, attitudes and policies that come together in a system to facilitate effective interaction in cross-cultural situations [36]. This article synthesizes available data on palliative care for CVD within the lens of culture and addresses the need for cultural competence in palliative care for cardiovascular disease, challenging health professionals to move from ritualistic considerations in care delivery to issues of access and equity in an environment of cultural competence. We have integrated the available literature within the context of a social-ecological model.

## THE SOCIAL-ECOLOGICAL MODEL

The social-ecological model is a theory-based framework for understanding the reflexive, dynamic and interactive effects of factors [37]. This approach promoted by Bronfenbrenner has been widely adapted in the health and social services to provide an understanding of the reciprocal transactions occurring between individuals and their social environments. Such an approach is particularly important when considering the influence of culture within the context of the healthcare system. Using this model, we consider that factors at the level of the individual, provider and healthcare system can influence how culture impacts on palliative care services and uptake (see Fig. 1). In the section that follows, we apply the social-ecological framework to highlight the interaction of forces that drive cultural factors and influence access to palliative care and the capacity to meet the needs of individuals and families.

The first level of the social-ecological model identifies personal characteristics at the level of



**FIGURE 1.** Social-ecological framework for palliative care.

the individual. In addition to unique biomedical characteristics, this sphere pertains to the individual's knowledge, attitudes, beliefs and behaviors that influence acceptance of palliative care. Individual's knowledge, attitudes and beliefs are moderated by sociocultural factors as well as peer experiences and prior exposure to palliative care services. However, it is essential not to lose sight of individual variability among people of the same sociocultural background and to avoid making generalizations based on perceived group characteristics. Specific approaches to changing individual's knowledge, attitudes, beliefs and behaviors may include education and information sessions [38], strategies such as question prompt lists [39], as well as creating awareness through social marketing strategies undertaken by professional organizations. Other examples of individual-level interventions include strategies to decrease stigma and increase the acceptability of assessment by a palliative care team and the interventions they suggest [40]. An important consideration in some culturally and linguistically diverse populations is that the needs of the individual (and particularly decision-making) may be deferred to family members based upon social mores [6,32]. Moreover, it is also important to consider the use of traditional medicines in specific population groups [41].

## INTERPERSONAL

This second level examines the relationships that may increase the uptake of palliative care, and it is in this sphere where culture plays a critical role [42]. In

**Table 1.** Recommendations for clinical practice

Understand the patient's needs and wishes for end-of-life care
Encourage patients with life-limiting cardiovascular disease to consider advance care planning and have discussion with their wider family early in planning their health journey
Identify the cultural, linguistic and spiritual needs of care recipients and their families, including rituals and practices around sickness, death and dying
Ascertain the level of comfort in discussing chronic illness, death and dying at the level of the individual and family members
Determine the patient's wishes about the role of family members in decision-making about care and treatment
Negotiate culturally appropriate strategies among the primary and specialist palliative care team(s)
Provide information in the preferred language and engage healthcare interpreters where appropriate
Ensure palliative care recipients and their families have access to culturally appropriate emotional support and spiritual support
Engage community health workers and faith-based and cultural communities where appropriate
Consideration of the cultural association of symptoms such as pain, breathlessness and existential distress

many culturally and linguistically diverse groups, decisions are made according to accepted principles, and nondisclosure of diagnosis is a particular challenge for palliative care health professionals and in some instances can create ethical dilemmas [32,43,44]. Programmes recognizing cultural influences on decision-making are pivotal for optimizing outcomes in many culturally and linguistically diverse communities [42<sup>■</sup>]. In many communities, faith-based advisors are important thought leaders in setting community norms and proactively engaging them in supporting palliative care interventions is an important consideration. The role of primary care and general practice is particularly important because, in culturally and linguistically diverse groups, these healthcare professionals are commonly more sensitive to patient and family needs and exert more influence than specialist services [32,45]. General practitioners may be selected by the patient because they are from his/her cultural group and can communicate in the home language [32]. A critical consideration is ensuring that primary healthcare providers understand the value and importance of a palliative approach in CVD [46]. Likewise, there is a need to understand cultural influences on any power imbalances and sex-based roles and how these may influence access to healthcare.

Advance care planning (ACP) is a patient-centered communication process which allows patients to discuss their values and preferences for future care with their families and health professionals so that decisions can be made in accordance with their wishes in the event they become unable to speak for themselves [47]. Conversations about ACP can be challenging for health professionals, families and patients [48]. Such conversations ideally do not take place during a time of crisis. Engaging faith-based leaders in ACP has shown considerable promise [49]. Models of shared decision-making require the

individual to be presented with options and their preferences elicited to enable collaborative decision-making [50]. In many cultural and religious groups, this process needs to be expanded to be inclusive of key decision makers in families and communities which may include community health workers and leaders of faith-based organizations [29,51]. Although similar acceptance of ACP across groups has been identified, this may depend on the level of acculturation [52<sup>■</sup>]. In developing economies, the role of community health workers ought not be underestimated [53<sup>■</sup>]. Leveraging interpersonal relationships and also the authority of key individuals can assist in improving approachability, availability, accommodation and appropriateness of palliative care models.

## COMMUNITY

The third level of the social-ecological model in Fig. 1 describes the settings in which palliative care is delivered and also where individuals live. Strategies at this level focus on impacting the social environment, by reducing social isolation, and improving economic and social circumstances [25<sup>■</sup>,54<sup>■</sup>]. Awareness of palliative care is commonly lower among minority ethnic groups, and the most socioeconomically disadvantaged. Particularly, in indigenous or first-nation communities, skepticism and mistrust of health services and therefore of palliative care is most pronounced [55,56]. This is manifested by African-Americans who are less likely to accept a 'Do Not Resuscitate' order. However, at the community level, and particularly in diasporas, there is the capacity to leverage social capital and resources for providing palliative care through engaging resilience and cultural factors [57,58<sup>■</sup>]. Engaging community navigators and community health workers is increasingly recognized as being important in engaging vulnerable populations [59,60].

## SOCIETY, POLICY AND SYSTEM

Societal factors include the health, economic, educational and social policies that entrench economic or social inequalities between groups in society, including in the most extreme case discrimination and racism [61,62]. These factors also include social and cultural norms that support the role of palliative care as a credible, valuable and important dimension of healthcare provision. The policy context is critically important in funding and ensuring access to palliative care services [63,64]. Sadly, many individuals with CVD do not have access to a palliative approach or to specialist palliative care. This gap largely occurs because palliative care as funding models does not promote early access and/or many healthcare providers do not have the confidence to initiate a palliative approach and/or promote access to specialist palliative care. There is a critical need for development of healthcare systems to provide an appropriate level of palliative care for individuals with CVD in accordance with need, supported by enabling policy and funding models; individuals and communities who are willing to accept the input of palliative care; and by healthcare providers who are not only skilled in palliative care but are also culturally competent. Training of healthcare staff in understanding the palliative approach is critical to ensuring access to palliative care [65]. Although evidence-based guidelines emphasize the importance of integration of palliative care in cardiovascular management, in reality this is not routinely implemented [2,66,67]. Considering opportunities and challenges for improving palliative care at the level of the individual, interpersonal relationships, community and society is crucial in promoting access to individuals with CVD from diverse backgrounds. Table 1 provides recommendations for practice and culturally appropriate and competent care on the basis of available data and guidelines. These strategies are congruent with the person-centered and comprehensive approach to palliative care in both primary and specialist care [68].

## CONCLUSION

Palliative care access and delivery is known to be poor across many nations and cultural groups, particularly for those with nonmalignant conditions. Death and dying is an important consideration in health service planning and delivery and because it is a highly culturally laden experience it presents both an opportunity and a challenge. Conceptually and philosophically, the holistic philosophy of palliative care is enabling of being inclusive of culture and the emphasis placed on communication is an important dimension of engagement. In

addition, palliative care providers are experienced in working through ethical dilemmas and conflicts. What is apparent from a review of contemporary literature is that culture is a critical dimension and should be part of the individual assessment of the needs of the individual and their family. The need for deliberation and seeking of solutions is an international phenomenon and underscores the growing importance of cultural pluralism in a globalized society. Extending the consideration of culture beyond the individual patient encounter to one that also considers the characteristics of health providers and community values raises is critical in improving access to quality primary and specialist palliative care. This is particularly important in emerging economies wherein the importance of palliative care for CVD is less well recognized.

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- of special interest
- of outstanding interest

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