Top Lang Disorders
Vol. 40, No. 3, pp. 278–296

A Human Rights Perspective on Palliative Care

Unraveling Disparities and Determinants Among Asian American Populations

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Purpose: Palliative care is regarded as fundamental to human dignity and falls under the definition of basic human rights. One considerable community of color whose needs are poorly understood consists of Asian Americans, including distinct priorities, expectations, and decision-making processes by diverse subgroups. The purpose of this work was to understand whether and to what extent unique considerations are understood among Asian American subgroups. **Method:** A scoping review was conducted among major scientific and academic databases. Broad search terms surrounding end-of-life care were combined with individual racial and ethnic identifiers encompassing Asian American subgroups. **Results:** Twenty-two articles met inclusion criteria and reflected diverse arrays of worldviews surrounding access to, utilization of, and desired outcomes from palliative care. Most articles focused on social orientations prioritizing family in disease disclosure and avenues of interventions sought with distinct patterns among subgroups. **Discussion/Conclusion:** A human rights framework emphasizing palliative and other end-of-life approaches to care may be inadequate to address unique considerations among diverse Asian American subgroups. Theorists and practitioners should incorporate practices of collectivist orientations and family contexts commonly found among these diverse communities. **Key words:** *Asian Americans*, *contextual factors*, *cultural sensitivity*, *end-of-life considerations*, *health disparities*, *palliative care*

UNIVERSAL HEALTH CARE as a human right has a long and complicated global history. The Universal Declaration of Human Rights is the foundation of this right (Gostin et al., 2018). Palliative care has a key role in this framework and should be a core part of any health system providing Universal Health Care (Gwyther et al., 2009).

In addition to palliative care being part of a structural framework for the human right to health care, it is a vital component of the practice of medicine and its goals. For example, the Hastings Center, in its 1999 report (Hanson & Callahan, 2000), made elimination of suffering and the pursuit of a peaceful death integral to the practice of medicine by placing these issues into its definition of the goals of medicine. Indeed, the effective practice of medicine is not merely the application of diagnostic reasoning but rather an interpretative and dialogic encounter that seeks to support patients in finding meaning in their illnesses and providing comfort when there is no cure. Relieving pain and suffering is core to palliative care and is sharply defined by cultural and social beliefs and practices. If access to palliative care is truly a fundamental right, cultural and social issues that frame

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The authors have indicated that they have no financial and nonfinancial relationships to disclose.

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DOI: 10.1097/TLD.0000000000000222

human suffering in the face of illness and death must be understood.

Myriad factors influence access to and utilization of palliative care. A recent literature review found three key barriers to integration of palliative services into management of care of patients with serious illness, which encompass domains of education, implementation, and policy (Aldridge et al., 2016). Furthermore, disproportionate gaps in knowledge and contextual determinants—absence of culturally and linguistically appropriate services, lack of diverse personnel, mistrust of the health care system, and low health literacy—exacerbate disparities among racial and ethnic minorities with respect to accessing high-quality and sensitive end-of-life (EoL) care (Johnson, 2013).

DISPARITIES IN PALLIATIVE AND EOL CARE

As in many health-oriented disciplines, disparities in adverse outcomes are a cause for concern, especially when the existence and persistence of such differences are avoidable and thus violate notions of social justice (Jones et al., 2019). A recent scoping review of disparities in palliative care found that significant differences exist among racial and ethnic minorities in the United States (Gardner et al., 2018). Moreover, cultural perspectives on approaches to EoL were key drivers on whether and how palliative measures were sought by patients and addressed by providers in a sensitive and appropriate manner. The persistence of inequitable access to and lack of utilization of palliative care by racial and ethnic minorities underscores the need for providers trained in diverse disciplines. Such strategies must be bolstered by supportive health care systems to be adequately equipped to increase awareness of and provide culturally sensitive EoL services to individuals of diverse backgrounds.

CONSIDERATIONS FOR ASIAN AMERICAN POPULATIONS

Based on the authors' own experiences in scholarship intersecting ethical approaches, health disparities, and community-engaged health promotion strategies among diverse Asian American subgroups, it is clear that unique perspectives and experiences must be understood for development and delivery of effective palliative programs. For instance, language barriers may expand beyond translation to understanding symptoms and disease within unique cultural frameworks of illness, whereas low-income immigrants may be resistant to seek health care due to consequences of public charge legislation, while community stigma may preclude seeking of care or clear presentation of diagnostic criteria for mental disorders (Jin et al., 2002). Often, such considerations are compounded by the backdrop of a mythical and counterproductive "model minority" categorical ascription (Stella et al., 2016).

In this article, issues and data pertaining to palliative care access and EoL considerations among Asian Americans are highlighted. The U.S. Census Bureau (2020) defines an Asian individual as a "person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam." A focus on these communities of color is warranted, given that, as a whole, they are the most rapidly growing racial/ethnic population in the United States (Lopez et al., 2017). Numbering more than 20 million, Asian Americans are expected to be the largest racial/ethnic group in the United States by 2055, surpassing Latinos. Three subgroups (Chinese, Asian Indian, and Filipino) comprise almost two thirds of the Asian American population. In addition, Vietnamese, Koreans, and Japanese number more than 1 million in population in the United States. Although as a whole, Asian Americans exhibit a favorable socioeconomic profile with respect to median income and proportion of the population with college education, such characteristics are bimodally distributed (Museus et al., 2013). More than half of adult Asian Americans are foreign-born. Many immigrants entered the United States after the passage of the 1965 Immigration & Naturalization Act, which abolished quotas for entrants from specific countries. As such, the mean age of Asian American immigrants is higher than native-born, with the percentage of those 65 years and older growing significantly between 2000 and 2010 (Ramakrishnan & Ahmad, 2014). Coupled with a higher propensity to life in a multigenerational household, this aging profile has important implications for the provision and quality of health care services at later stages of the life course, especially with the considerable proportion with limited access to quality health care and dependence on adult children for support.

A recent literature scan of health disparities research found that a considerable proportion of studies continue to aggregate data among this population (Ponce et al., 2018). Likewise, all studies included in the aforementioned scoping review considered Asians (or Asians and Pacific Islanders) as a monolithic group, thus obscuring meaningful differences among the diverse communities that fall under this umbrella categorization. Indeed, it has been shown that the disaggregation of data among this population reveals divergent patterns of outcomes and risks (Holland & Palaniappan, 2012). For example, all but three major subgroups (Asian Indian, Filipino, and Japanese) reflect poverty rates of 10% or higher, with more than 20% of Nepalese, Hmong, Bangladeshis, and Burmese living in poverty (Joint Economic Committee Democrats, n.d.). These patterns are exacerbated for individuals 65 years and older who identify with specific Asian communities (Tran, 2017). Similarly, Asian Indians, Chinese, Filipinos, Korean, Vietnamese, and other Asians had health uninsurance rates higher than 10%—with the latter three greater than 24%—prior to the passage of the Affordable Care Act, although most were cut by more than half after implementation of the law (Park et al., 2018). A brief summary of disaggregated data reflects considerable differences in rates and mortality from diabetes, cardiovascular disease, cancers, and dementia (Mehta & Yeo, 2017; Nguyen et al., 2015; Pu et al., 2017; Thompson et al., 2016). Many of these conditions occur in later stages of life, of which some may be untreatable. Lack of granular data precludes a full understanding of population health inequities and, more importantly, the development of targeted programs and policies that mitigate and eliminate preventable disparities (Ghosh, 2010; Islam et al., 2010), although funding and resources to glean such differences remain woefully lacking (Chen, 2019; Đoàn et al., 2019). These considerations affect the development of tailored EoL strategies that are not represented by a superficial "Asian" categorization used commonly in scientific and health research.

ROLE OF HEALTH SYSTEMS AND PRACTITIONERS

Given the importance of approaches to and delivery of effective and culturally responsive palliative and EoL care among diverse populations, the purpose of this work was to understand whether and to what extent unique considerations within this domain of human rights are understood among Asian American subgroups. For instance, two recent population-based studies demonstrate lower use of advanced care directives (ACDs) among communities of color but did not include Asian Americans in their analysis (Huang et al., 2016; Portanova et al., 2017). Although the first of these studies used a nationally representative data set with sufficient numbers of African Americans and Hispanics for subgroup analyses, small sample sizes masked data reflecting ACD adoption among Asian Americans, American Indians, and Pacific Islanders. As such, this review specifically aimed to fill a gap in understanding of whether and how palliative care and other EoL interventions are accessible to and utilized by diverse Asian American subgroups. For health practitioners, health care delivery systems, and health policy makers, recognition of unique cultural factors in the context of human rights principles is instructive for the development of strategies. This allows access to palliative care emphasizing comfort and compassion for individuals, families, and communities experiencing physical and social challenges present during EoL. Recognition of complex and dynamic contextual environments governing discussions around and provisions of palliative care is instructive to enhance education and training for practitioners, such as speech–language pathologists (SLPs), psychologists, and psycholinguists, engaged in EoL matters with diverse populations to reduce disparities in access, quality, and utilization. For instance, SLPs play important roles in consultation with families, as well as clinical teams regarding communication strategies and tools in EoL situations while providing assistance to optimize function and facilitate satisfaction for patients receiving palliative care (Pollens, 2012; Toner & Shadden, 2012). The American Speech-Language-Hearing Association (ASHA) has underscored the integral role SLPs play in enhancing functioning and communication in patients receiving EoL care (ASHA, n.d.), as well as in the provision of supportive care surrounding emotional and existential issues such as those related to spirituality (Chahda et al., 2017). As such, this research provides insight into cultural considerations for such health care providers serving Asian American communities.

METHODS

A scoping review was conducted using key search terms in relevant databases of scientific literature. Specifically, broad and granular population identifiers ("American" plus each of the following: "Asian," "Asian Indian," "Bangladeshi," "Chinese," "Filipino/a," "Japanese," "Korean," "Nepali," "Pakistani," "Thai," and "Vietnamese") were combined with "palliative" or "end of life" as search terms. The databases from which literature was sought included PubMed, CINAHL, and PsycINFO. The database of Sociological Abstracts was also searched, but all relevant literature found in this database were duplicates of those identified in the other three major databases. An undergraduate research assistant initially screened articles by title and abstract to determine whether foci of studies involved empirical data—qualitative, quantitative, or mixed-methods—elucidating unique patterns and predictors of relevant palliative or EoL measures or domains of inquiry among specific Asian American subgroups. An initial list of articles was subsequently reviewed and refined by the lead author. The lead author replicated the literature search with identical terms to ensure the literature scan did not miss any research relevant to this review.

Articles were excluded if they focused exclusively on issues of palliative or EoL care among Asians outside of the United States. In addition, conference abstracts, dissertations or theses, or any other forms of "gray literature" were not included as, notwithstanding the existence or quality of peer review, there was no systematic manner in which a comprehensive search could be executed. Studies were also not included if they solely compared outcomes with another ethnic group without providing data that underscored social and cultural factors that may account for differences. Finally, research that primarily focused on experiences or perspectives of providers, or singular case studies that did not serve as appropriate or credible proxies for representation of contextual influences or outcomes directly related to the topical focus of this review, was not considered.

RESULTS

After exclusion of 10 articles from the initial search due to the previously mentioned conditions, a total of 22 articles were found to meet the inclusion criteria for this review. Table 1 provides a synthesis of study designs, target populations of interest, and a summary of findings for each of the included studies.

Table 1. Description of studies included in scoping review

Authors	Population(s)	Sample Characteristics	Design	Summary Findings
Berkman & Ko, 2009	Koreans	26 seniors (New York, NY)	Quantitative (convenience sample)	• Full disclosure among prognosis, symptoms, and expectancy was expected from most (particularly later in disease progression) • Those with poorer mental health more hesitant about disclosure • Most did not want information about lifesaving treatment but did want information about palliative options
Bito et al., 2007	Japanese	122 immigrants and residents/ patients in Japan (Los Angeles, CA)	Qualitative (focus groups)	• Family should be notified first; patients sometimes or usually next • Decisions should be made by family members, sometimes with guidance from physician or patients themselves • Preference is for sudden death over prolonged or troublesome EoL intervention • ACDs are seen as important and lessen family burden
Blackhall et al., 1995	Koreans	800 seniors (Los Angeles, CA)	Quantitative (convenience sample)	• Strong belief that patients should not be informed of terminal illness, nor make decisions about EoL • Family members should be final decision-makers about life support interventions
Blackhall et al., 1999	Koreans	800 seniors (Los Angeles, CA)	Quantitative (convenience sample)	• Positive attitudes toward life support, but no personal desire to prolong life • Such interventions were seen as mechanisms for children to fulfill duty

(*continues*)

Table 1. Description of studies included in scoping review (*Continued*)

Authors	Population(s)	Sample Characteristics	Design	Summary Findings
Chi et al., 2018	Chinese	14 seniors, nine adult children, seven health care providers (San Francisco Bay Area, CA)	Qualitative (key informant interviews and observations)	• EoL discussions should be raised early • Permission from patients to broach EoL subjects by providers important; provision of longevity and blessings important • Scenarios and personal experiences with EoL instructive
Doorenbos & Nies, 2003	Asian Indian Hindus	45 immigrants (Midwestern United States)	Quantitative (convenience sample)	• Females and those with individualistic decision-making style increased the likelihood of ACD completion • Strong religious affiliation and collectivist orientation negatively correlated with ACD completion
Gao et al., 2015	Chinese	385 seniors (Phoenix, AZ)	Quantitative (convenience sample)	• Most were unaware or completed ACDs • EoL decisions guided by assessment of burden on family • Physicians were seen as influential in initiating EoL discussions
Khosla et al., 2016	South Asians	57 providers for ill patients (Midwestern United States)	Qualitative (focus groups)	• General reluctance to use pain medications • Limited access, lack of education of benefits, skepticism of value play a role • Preference is to use spiritual approaches
Khosla et al., 2019	South Asians	57 providers for ill patients (Midwestern United States)	Qualitative (focus groups and key informant interviews)	• Family decision making is norm (primary is usually adult children or spouse) • Lack of awareness and negative impressions of palliative care are common • Higher levels of education and longer tenure in the United States influence autonomous decision-making • Providers are often conflicted between patient rights and family preferences

(*continues*)

Table 1. Description of studies included in scoping review (*Continued*)

Authors	Population(s)	Sample Characteristics	Design	Summary Findings
Ko & Berkman, 2010	Koreans	23 seniors (New York, NY)	Qualitative (focus groups)	• ACDs are uncommon • Role of children in decision making is complex as to receptivity about EoL discussions, determination of final designee, and fear about whether final wishes would be heeded
Ko & Lee, 2009	Koreans	112 seniors (New York, NY)	Quantitative (convenience sample)	• Lack of specificity in EoL instructions • Most EoL communications were with family, rarely with health professionals • Observations of and experiences with illness predicted initiation of EoL conversations
Kwak & Salmon, 2007	Koreans	20 seniors 16 caregivers (West Central Florida)	Qualitative (focus groups)	• ACDs not needed or followed (although instructive); informal discussions seen as more important • Perception that children will adhere to parents' final wishes • Physicians regarded as facilitators of such conversations • Observations of and experiences with illness predicted initiation of EoL conversations • General community sentiment of avoiding negative topics between parents and children • Preference for death at home
Lee et al., 2018	Chinese	60 community members (state of Maryland)	Qualitative (focus groups)	• Freedom from pain and suffering highly valued • Death with dignity involved prayer, having family present, and not being a burden • Trust in doctor important
Matsui & Braun, 2009	Japanese Hawaiian	112 seniors (state of Hawaii)	Quantitative (convenience sample)	• Most discussed EoL care with the physician or family • Hospice was preferred for EoL care

(*continues*)

Table 1. Description of studies included in scoping review (*Continued*)

Authors	Population(s)	Sample Characteristics	Design	Summary Findings
Mondia et al., 2012	Filipino, Chinese, Korean Chinese	Three patients with cancer and family members (state of New York)	Qualitative (case studies)	• Grief planning and process influenced by collectivist values, particularly around generational hierarchy and gendered obligations
Mori et al., 2018	Japanese	441 community members (New York, NY, and state of West Virginia)	Quantitative (convenience sample)	• For Japanese in the United States, physicians initiating conversations and full disclosure of illness to patients important • Preference for inquiry may only be seen as acceptable if initiated by the patient
Ngo-Metzger et al., 2008	Chinese, Japanese, Filipino, Hawaiian/ Pacific Islanders, other Asians	2,145 Chinese Americans, 3,510 Japanese Americans, and 1,781 Filipino Americans 322 other Asian Americans (states of Connecticut, Hawaii, Iowa, New Mexico, and Utah)	Quantitative (representative sample of Medicare beneficiaries from SEER Database with terminal cancer)	• All groups had lower hospice enrollment than Whites • Filipinos enrolled earlier and had longer hospice stays • Japanese enrolled later
Radhakrishnan et al., 2017	Asian Indians	47 established immigrants (Central Texas)	Mixed-methods (convenience sample with pre/postintervention survey and focus groups with follow-up interviews)	• Conversation game increase rates of and motivation for ACD completion • After 3 months, most had completed one ACD-related behavior and almost half discussed EoL issues with loved ones

(*continues*)

Table 1. Description of studies included in scoping review (*Continued*)

Authors	Population(s)	Sample Characteristics	Design	Summary Findings
Radhakrishnan et al., 2019	Asian Indians	36 immigrant seniors, caregivers, and providers (Central Texas)	Qualitative (focus groups)	• Barriers to engaging in EoL decisions included prior lack of awareness of ACP, good health status, lack of access to linguistically and health literacy-tailored materials, health care provider hesitation to initiate discussions on ACP, trust in health care providers' or oldest sons' decision making, busy family caregiver work routines, and cultural assumptions about filial piety and after-death rituals • Facilitators to engagement involved personal anecdotes in a neutral, group-based community setting and incentivizing discussions of ACD by including long-term care planning
Rao et al., 2008	Indo-Caribbean Hindus	44 seniors (Queens, NY)	Quantitative (convenience sample)	• Low levels of knowledge of ACDs • Although ACDs well regarded, deemed unnecessary if family members are aware of wishes • Patients and family should be notified of diagnosis and engage in decision making • Negative views about life-prolonging care
Rhee & Jang, 2020	Asian Indians, Chinese, Korean, Vietnamese, other Asians	499 established immigrants aged 60+ years (Austin, TX)	Quantitative (convenience sample)	• Compared with Chinese, all other subgroups had lower odds of designating SDMs • Belief against speaking of death had no effects on the likelihood of SDM designation • Increased length of time and English proficiency increased odds of SDM designation
Sharma et al., 2012	South Asians (Hindus, Sikhs, and Buddhists)	11 educated middle-aged/older immigrant and U.S.-born adults (Midwestern United States)	Qualitative (focus groups)	• Perceptions of ACD use low • Diverse attitudes around death/dying; some felt suffering was part of religious consequences • Debate about whether terminal diagnosis should be conveyed to patients • Family, especially adult sons, were seen as decision-making entity, given family and economic burdens

Note. ACD = advanced care directive; ACP = advanced care planning; EoL, end of life; SDM = surrogate decision maker; SEER = Surveillance, Epidemiology, and End Results.

Of the 22 articles, 10 presented qualitative research, 11 were quantitative in nature, and one employed a mixed-methods approach. One of the studies included population-based sample, and the remainder involved convenience samples of community segments. Focus groups were involved in eight of the 10 qualitative research articles as well as the mixed-methods study, whereas the remaining involved key informant interviews, observations, and multiple case studies.

Characteristics of samples from studies in review

The majority of participants in studies included in this review were community-dwelling individuals; however, there were some participants who were actively receiving care. Three studies reported experiences of providers who serve large numbers of specific Asian American patients and, based on observations and interactions, were able to provide common perspectives and decisions regarding palliative care; one of these was a mixed-methods study involving senior immigrants, caregivers, and providers identifying as or serving a major Asian community. Only two involved populations of patients diagnosed with a terminal condition (cancer). Fourteen of the 22 studies did not present information on whether participants were immigrants, whereas the remainder largely focused on respondents born outside of the United States. Most investigations involved senior citizens (aged at least 50 years and older). Limited information was provided about other sociodemographics.

With respect to consideration of Asian American subgroups, residents of Chinese, Korean, and South Asian origin were the most studied populations, followed by Japanese and Filipinos. A relative emphasis on these populations is logical, given that recent demographic data suggest that the Asian American subgroups largest in size are Chinese, Asian Indians, and Filipinos (Lopez et al., 2017). Some studies focused on very narrow communities, such as biracial Korean Chinese and Hindus who identified as Asian Indian or Indo-Caribbean. Nineteen of the 22 studies included in this review focused on singular populations, with the remaining three conducting in-depth comparative analyses of multiple Asian American subgroups. Only one study assessed the impact of an intervention on changing behavior or motivation related to EoL planning.

Measures of palliative and EoL care

A variety of measures and domains related to palliative or EoL care were examined in studies featured in this review. Although the International Classification of Functioning, Disability and Health (ICF) perhaps provides the most granular insight into specific EoL-related variables, the specificity of measures precluded a meaningful comparative analysis based on such measures (Kostanjsek, 2011). The National Quality Forum (NQF) is a nationally recognized nonprofit organization that analyzes and endorses specific health care quality measures that are used for public reporting and performance purposes in private sector and state programs (Moody-Williams, 2020). Eight of the 22 articles meeting inclusion criteria focused on specific outcomes measures endorsed by the NQF (2012). Such quantitative outcomes included a lower likelihood of enrollment in hospice among Asian Indian, Chinese, Japanese, Filipino, and other Asian Medicare beneficiaries (compared with a referent group of Whites) (Ngo-Metzger et al., 2008). Moreover, among Asian Americans who elected for hospice care in this study, Filipinos enrolled earliest postdiagnosis (with longer stays) whereas Japanese participants enrolled considerably later. Another study (Rhee & Jang, 2020) found low rates (8.2%–31.2%) of designating a surrogate decision maker (SDM) among Asian Indians, Chinese, Korean, Vietnamese, and other Asians, with odds of designation increasing among those with higher education, more stable financial situations, health insurance, and tenure of residence in the United States.

A considerable number of studies explored understanding and use of ACDs. A multiethnic investigation found overall low levels of knowledge surrounding ACDs among most Asian American subgroups (Rhee & Jang, 2020). This was also found to be true in a very specific community of Hindus of South Asian origin who immigrated to the Caribbean and are descendants of Indian indentured servants under the British colonial rule. A broader community of Asian Indian Hindus had less than 10% ACD completion rate, with a minority of participants desiring to complete ACDs (Doorenbos & Nies, 2003). These patterns were supported by other research that found completion of ACDs to be uncommon among Chinese (Gao et al., 2015) and Koreans (Ko & Berkman, 2010), with a similar perception of low ACD completion rates among Asian Indians (Sharma et al., 2012). This review found that many of the reasons for lack of ACD use or completion were often based on a structure of decision making surrounding EoL matters that prioritize the wishes and actions of family over the individual (Blackhall et al., 1995; Khosla et al., 2019; Ko & Lee, 2009; Sharma et al., 2012). This pattern was particularly pronounced among adult children of Koreans (Ko & Berkman, 2010; Kwak & Salmon, 2007). Echoing these barriers related to family dynamics and hierarchies, South Asians reported lack of completion or motivation to complete ACD due to lack of linguistically and culturally appropriate materials and hesitation of providers to broach sensitive EoL topics (Radhakrishnan et al., 2017).

Expectations of health care providers in EoL care

The experiences and perspectives of how physicians were and should be involved in the process were variable. For instance, Koreans reflected on rare interactions with health care providers regarding EoL considerations, although physician roles were perceived as being instructive (Ko & Berkman, 2010; Kwak & Salmon, 2007). In contrast, a sense of trust in medical doctors was desired among Chinese (Lee et al., 2018) and initiation of communications regarding these sensitive topics was preferred to be undertaken by physicians (Gao et al., 2015). Furthermore, participants reported that candid interactions and decisions were only meaningful if broached in a respectful and deferential manner (Chi et al., 2018). Among this subgroup, personal experiences with palliative care among providers and scenarios involving various EoL outcomes were considered beneficial. The value of physician-directed discussion was similarly concluded among Japanese, yet a considerable proportion of respondents wished to engage in such conversations only if initiated by the patient (Mori et al., 2018). Results from one study examining perspectives of clinicians who served South Asian patients found that participating providers were conflicted between whether patients or family members should be engaged first about EoL matters; such processes were often dictated by adult children and/or spouses, particularly those involving poor prognoses (Khosla et al., 2019). Echoing deference to family members in addressing EoL considerations, another study investigating awareness and completion of ACDs among Asian Indians found that physicians of this ethnic group were often apprehensive to initiate such conversations due to perceptions that conversations surrounding death caused undue alarm and anxiety (Radhakrishnan et al., 2017).

Influences of contextual perceptions of death and dying on EoL care

Most studies included in this review explored the social contexts in which considerations (or lack thereof) of palliative care were understood and acted upon by Asian Americans. For instance, Indo-Caribbean Hindus had generally negative views about life-prolonging or sustaining care in the case of terminal illness (Rao et al., 2008). In contrast, a broader group of South Asians of Hindu, Buddhist, and Sikh faiths exhibited a common perception that EoL suffering was a standard manifestation of preordained faith-related consequences, although they felt that belief should not preclude clinical intervention (Sharma et al., 2012), given shared contextual beliefs around life, death, and rebirth as part of a broader spiritual cycle. This finding was further supported by the strong inverse correlation between a strong Hindu religious affiliation and completion of ACDs (Doorenbos & Nies, 2003). Koreans shared many similar sentiments about avoiding discussions of death (Kwak & Salmon, 2007). This seemed to be largely due to apprehension about whether final wishes of the deceased would ultimately be carried out (Ko & Lee, 2009). However, studies were inconsistent about whether curative or palliative care was preferred by either Korean patients or family members (Blackhall et al., 1995, 1999). Individuals of Chinese descent sought freedom from pain and suffering, as well as minimizing burden of surviving family members, as a key driver of decision making involving death with dignity (often involving prayer) and thus EoL discussions within medical settings were desired to be held early on during the clinical trajectory (Chi et al., 2018; Lee et al., 2018).

Patient notification and family decision making

A common tension found was a complex phenomenon surrounding whether patients or family members should be informed about a diagnosis requiring discussion of EoL care. This included varying levels of receptivity to any form of intervention, uncertainty about who should make the final decision about pursuit of palliative or curative approaches, and what factors should be considered in determining the ultimate course of action. This review found that patients and older individuals of South Asian, Japanese, and Korean origin conveyed sentiments that patients should be notified after family members, if at all, regarding a terminal diagnosis (Bito et al., 2007; Blackhall et al., 1995; Sharma et al., 2012). The study in which researchers focused on Japanese participants found that many in the community wished for a sudden and unanticipated death to avoid a prolonged or troublesome EoL process. Many Asian American subgroups, particularly South Asians and Koreans, desired EoL discussions and decisions to be undertaken in family settings, often amplified by a mistrust of physicians and health care systems. Less specific or informal instructions about whether and how palliative care should be employed were a common phenomenon. Decisions around EoL care were often based on competing and conflicting priorities among patients and relatives, whether perceived or actual, as seen among Koreans (Kwak & Salmon, 2007).

A multiethnic investigation found that a collectivist cultural orientation with embedded notions of proper behavior (e.g., normative gender roles surrounding male decision-making) and stigmatized conditions (e.g., shame and embarrassment associated with overt emotion before strangers, such as providers) among Filipino, Chinese, and Korean Chinese communities influenced reactions to impending death (Mondia et al., 2012). More specifically, expectations of filial duty, complicated by gender hierarchies and intergenerational conflict, resulted in ineffective and unsatisfactory strategies to address EoL care. Finally, there were conflicting interpretations about the value of life-prolonging care, hospice, and the relative effectiveness of pharmaceutical versus spiritual interventions (Berkman & Ko, 2009; Khosla et al., 2016; Matsui & Braun, 2009; Radhakrishnan et al., 2017). Notwithstanding these important distinctions, there was overall agreement that EoL care should happen within the home and burden to family members should be minimized in any chosen intervention strategy. For instance, the only intervention study included in this review found that a culturally appropriate conversation game, consisting of open-ended questions to stimulate discussion among family and community members and incorporating contextual considerations of social obligations, increased rates of and motivation for ACD completion (Radhakrishnan et al., 2019).

DISCUSSION AND CONCLUSION

Human rights scholars have determined that, akin to public health, access to and provision of palliative care is a human right (Gwyther et al., 2009; Radbruch et al., 2013). An international consensus committee (Brennan et al., 2008) determined that the core obligations of such a theoretical proposition entail five elements: (1) creation and implementation of palliative care policies; (2) equity of access to services, without discrimination; (3) availability and affordability of critical medications, including opioids; (4) provision of palliative care at all levels of care; and (5) integration of palliative care education at all levels of the learning continuum from informal caregivers to health professionals. Denial or unequal access to these fundamental provisions can be surmised to be a violation of these rights and thus requires that providers develop a keen understanding of disparities and the fundamental determinants of disproportionate outcomes. To that end, this review provides insight from a review of the scientific literature, namely, whether and how palliative care and other EoL interventions are accessible to and utilized by diverse Asian American subgroups.

Need for uniform disaggregation of Asian American data

The classification of Asian Americans, often expanded by the inclusion of Pacific Islanders, as a monolithic population in and of itself violates a basic premise of health equity. If human rights are truly to be distributed equitably among diverse communities, population-level data must reflect meaningful racial and ethnic categories to understand distinct patterns of risks and outcomes experienced by such groups, especially those who are minorities. This review found only one nationally representative study in the United States that disaggregated Asian subgroups. Researchers authoring that study found important differences in rates of hospice use, median length of stay, and time of enrollment in hospice care relative to date of death (Ngo-Metzger et al., 2008). However, that investigation only focused on participants in the Surveillance, Epidemiology, and End Results (SEER) Program, which limited the inquiry to only those diagnosed with cancer and thus did not include a large segment of the Asian American population that would require access to palliative care for other conditions. It is imperative that disaggregation of Asian American data, along with other major racial and ethnic populations, be conducted in a uniform and timely manner. This would allow health researchers, including those concerned with disparities in EoL care, to truly understand areas where further attention is warranted. This disaggregation is particularly critical, given the complexity, variety, and nuance associated with EoL issues and palliative care in the communities that are typically grouped as "Asian." Moreover, our findings that many Asian American subgroups, such as those with a considerable presence in the United States (e.g., Vietnamese and Filipinos), were not absent from studies or combined with other communities, which limit understanding of key influences on palliative and EoL care among specific subgroups.

Contextual strategies for EoL care among diverse Asian American communities

Another area of further discussion is clearly delineating what constitutes culturally sensitive palliative care. Much of the literature focuses on empirical outcomes related to pain management, surrogate decision-making, and ACDs. These are important measures that reflect the provision of relief and compassionate care for individuals suffering from pain and discomfort and the presence of proactive efforts of individuals to make their desires known, clinically and legally, before losing capacity to do so. This review underscores that, although some Asian American subgroups are aware of and highly regard the importance of such measures, utilization remains low overall, rates differ considerably by subgroup, and the reasons for these differences are multifactorial. Study findings are consistent with a government report indicating that Asian Americans, as a whole, prefer family-centered decision-making that de-emphasize self-interest (Wilkinson et al., 2007). The family orientation common among many Asian American communities poses a conceptual challenge to individually embedded outcomes, including formal designation of those empowered to make legal decisions on behalf of another person. Specifically, cultural values around shared decision-making are complicated by normative characteristics around gendered and generational hierarchies of authority, which often contradict Western notions of autonomy that are placed with the person. Thus, a right to palliative care and EoL planning, including understandings of EoL considerations, must be sensitive to social orientations of collectivism in which decisions and their associated benefits and consequences are assessed and acted upon at a group level. This sensitivity to cultural and family requirements is included in the right to palliative care, given the indivisibility of human rights, principles of nondiscrimination, and of participation. For instance, this review highlights how filial and social burden attributable to either palliative or curative interventions is the driver of decisions made by patients or families. This considerably influences those stakeholders to initiate or engage in relevant discussions with providers surrounding death, enter or stay in hospice, pursue pain relief through medication, or turn to faith as a source of comfort or relief. These cultural considerations fall squarely within the accepted definition of palliative care, as explicated by the World Health Organization ([WHO], 2002), yet the lack of contextual assessment of interpersonal and social influences on and consequences of an individual's EoL prospects must be substantively incorporated in any discussion of palliative care disparities and application of human rights. This is not possible without the standard disaggregation of data reflecting outcomes and factors reflecting the diversity of Asian American subgroups.

Considerations of patient autonomy and interpersonal decision-making

A final observation from this review that merits further theoretical, methodological, and practical consideration is that study findings reflect contrasting viewpoints of whether a terminally ill patient should be informed of his or her condition. Tensions between patient autonomy, professional ethics, and cultural conditions are replete in the medical and health literature, with juxtaposed positions of paternalism and self-determination supporting or detracting from unequivocal practices of clinical disclosure (McCabe et al., 2010). Neither a simple nor definitive solution to this long-standing ethical dilemma is possible, but the notion that this is a straightforward or binary decision must be avoided. The complexities of decision making in EoL care are not unique to the experience of communities included in the analysis and support a conclusion that one size simply does not fit all. There is a path forward that does not apply a simple binary choice of autonomy versus nonautonomy. Decision making in a health care setting is very complex and conceptions of autonomy are equally complex (Dive & Newson, 2018; Radha Krishna & Alsuwaigh, 2015; Tai, 2013). To this end, an ecological framework may be insightful insofar as it recommends a multilevel approach to public health and clinical interventions (Pask et al., 2018). A study of care for patients with amyotrophic lateral sclerosis in Australia found that acknowledging the interplay between individual and interpersonal decision-making within a facilitative structural environment (e.g., provision of interprofessional and multidiscliplinary team-based approach to care delivery) was a critical influence on the management of symptoms and quality of life (Hogden et al., 2012). Another investigation of EoL issues surrounding terminal cancer among African Americans emphasized the importance of allowing for social decision-making to increase the capacity of patients to overcome any limitations in a patient's physical, emotional, or cognitive capacity (Campbell et al., 2011). It is critical that any linkage of palliative care and human rights take into account this complexity.

This review also underscores the effects of a narrow principled orientation. As a practical matter, the lack of an expanded framework is seemingly related to an amplified withdrawal of multiple Asian American communities from discussion, exploration, and initiation of any palliative care regimen. This constitutes an organizational and legal barrier to true access to compassionate EoL care if governing principles are dogmatically grounded in an individual basis of clinical care and individual patient autonomy. As demonstrated by the perspectives and behaviors of subgroups in this review, many members of this population are socially oriented to grant family members, especially adult children, the authority to make decisions about a patient's clinical course of actions. Some communities demonstrate a strong belief that patients not be told of terminal outcomes as it may actually accelerate physical and social degradation of life. For instance, among the two most predominantly featured populations in this review, Koreans had strong beliefs that patients should not be informed about their terminal illness and that family members such as the patient's oldest children should be the final decision-makers about life support and interventions, whereas Japanese preferred family to be notified before the patients. For Japanese, in particular, community members wished for sudden death, rather than placement on life support, to avoid imposition of burden on family. Principles and protocols that exclude incorporation of cultural value systems illustrated in this review may serve as an impediment to access or pursuit of all options that are congruent with the ideals of palliative care, particularly as they relate to psychological and spiritual aspects of care, quality of life, active engagement, family involvement, and course of illness.

Study limitations

This review is not without its limitations. Investigations of EoL care among Asians within global settings were not included, as the priority was on understanding access and provision of palliative care services within a U.S. context. Palliative care development varies tremendously across Asian countries, which may influence differences in awareness, understanding, and pursuit of palliative care by community members of diverse origins seen in this review (Yamaguchi et al., 2017). As this was an empirically oriented investigation, we did not employ a purely theoretical analysis, as our goal was to understand how contemporary frameworks intersecting human rights and palliative care were appropriately suited for and applied to the unique contexts faced by diverse Asian American communities in deciding upon, being provided, and/or pursuing relevant palliative strategies. It merits noting that most of the studies included in this review were convenience samples, often involving qualitative inquiry, thus limiting their generalizability to any specific Asian American community. This is amplified by a standard lack of description of key socioeconomic characteristics, such as income, educational attainment, and English proficiency, which preclude a full understanding of such key influences on full comprehension of the purpose and value of palliative care. On a related note, only two studies involved populations of patients diagnosed with terminal conditions. Thus, many of the results generated in this review could be speculative on the part of participants and not be grounded in practical experience or actual confrontations with EoL issues, including palliative care. Our review did not include doctoral dissertations, graduate theses, or other sources of "gray" literature, as it was not possible to be exhaustive in a rigorous scoping review. Nonetheless, the systematic inclusion of peer-reviewed publications provides evidence of not only a paucity of investigation surrounding EoL considerations for Asian American subgroups but also unique factors related to family and social orientations, particularly around autonomy, the tension between individual and group outcomes, and the authority of decision making.

Implications for health professionals

Study results suggest that targeted outreach and enhanced education are necessary for patients, family members, and a diverse array of health care providers (not simply physicians). For Asian Americans, messaging must be sensitive to family and social contexts that balance the needs of disclosure and patient autonomy against the cultural norms of collective decision-making valued in specific communities, as evidenced in this review. The burden of addressing such complex dynamics should not be put upon a single clinician. Instead, multidisciplinary teams that can draw upon applied sociological and ethical bases of knowledge to address EoL challenges may be best suited for this role. Teams can provide communication about both palliative and curative options early in the disease progression trajectory, as well as reciprocal consultations with other members of the care team. For instance, SLPs have been shown to be an underutilized clinical asset in such as capacity insofar as they may be able to navigate physical, cognitive, and social aspects of communication with the patient and family through comprehension of terminal prognoses and navigation of a course of care congruent with individual and family priorities within a cultural context (Pollens, 2004, 2012). More training should be provided for nonphysician clinicians and allied health practitioners, especially professionals representing diverse Asian American communities, to be actively engaged in EoL scenarios. This may include the expansion of training for practitioners to include courses in the health humanities and bioethics and a focus on legal and policy systems to provide for and in the U.S. context. Although beyond the scope of this review, parallel efforts should be employed with community- and faith-based organizations serving specific Asian American communities to facilitate increased awareness of EoL considerations, including the importance of ACDs and SDMs to ensure that individual and family priorities are documented in legal and administrative channels.

Academic researchers and clinical educators should continue using data-driven strategies to advocate for equitable access to and utilization of quality palliative care, especially among diverse populations. For instance, more rigorous research is needed to understand and quantify the value of increased federal reimbursement for nonclinical services. Such investigations should be expanded to the provision of palliative care in the context of advancing health equity among underserved populations. Other consumer protection regulations are warranted at the state and federal levels to ensure equal access to information and options regarding EoL. In concert with recommendations from the WHO (De Lima & Pastrana, 2016), health service providers must make available sufficient human resources and infrastructure to adequately respond to palliative care needs. This is of particular importance to care delivery systems serving diverse populations, as evidenced by the results generated by studies included in this review.

Findings from this review and their associated implications are not simply a theoretical exercise and warrant more attention as it pertains to comprehensive and culturally sensitive access to and provision of palliative care services. Theorists and practitioners alike should acknowledge and appreciate the cultural lens in which EoL is understood and approached by diverse populations that do not share an individual orientation to medical care. For Asian American subgroups specifically, a multifaceted strategy sensitive to such considerations must be employed with respect to provider–patient–family communication as well as delivery of services that are sensitive and appropriate to the worldviews described in this review.

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