COURSE #97363 — 5 CONTACT HOURS/CREDITS RELEASE DATE: 09/01/21 EXPIRATION DATE: 08/31/24

Cultural Meanings of Death and Dying

HOW TO RECEIVE CREDIT

- Read the enclosed course.
- Complete the questions at the end of the course.
- Return your completed Evaluation to NetCE by mail or fax, or complete online at www.NetCE.com. (If you are a physician, behavioral health professional, or Florida nurse, please return the included Answer Sheet/Evaluation.) Your postmark or facsimile date will be used as your completion date.
- Receive your Certificate(s) of Completion by mail, fax, or email.

Faculty

Alice Yick Flanagan, PhD, MSW, received her Master's in Social Work from Columbia University, School of Social Work. She has clinical experience in mental health in correctional settings, psychiatric hospitals, and community health centers. In 1997, she received her PhD from UCLA, School of Public Policy and Social Research. Dr. Yick Flanagan completed a year-long post-doctoral fellowship at Hunter College, School of Social Work in 1999. In that year she taught the course Research Methods and Violence Against Women to Masters degree students, as well as conducting qualitative research studies on death and dying in Chinese American families. (A complete biography appears at the end of this course.)

Faculty Disclosure

Contributing faculty, Alice Yick Flanagan, PhD, MSW, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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Division Planners/Director Disclosure

The division planners and director have disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

Audience

This course is designed for physicians, nurses, social workers, therapists, mental health counselors, and other members of the interdisciplinary team who work with diverse racial and ethnic minority groups and their families during the end of life.

Accreditations & Approvals

JOINTLY ACCREDITED PROVIDER™
INTERPROFESSIONAL CONTINUING EDUCATION

In support of improving patient care, NetCE is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

As a Jointly Accredited Organization, NetCE is approved to offer social work continuing education by the Association of Social Work Boards (ASWB) Approved Continuing Education (ACE) program. Organizations, not individual courses, are approved under this program. Regulatory boards are the final authority on courses accepted for continuing education credit.

NetCE has been approved by NBCC as an Approved Continuing Education Provider, ACEP No. 6361. Programs that do not qualify for NBCC credit are clearly identified. NetCE is solely responsible for all aspects of the programs.

NetCE is recognized by the New York State Education Department's State Board for Social Work as an approved provider of continuing education for licensed social workers #SW-0033.

This course is considered self-study, as defined by the New York State Board for Social Work. Materials that are included in this course may include interventions and modalities that are beyond the authorized practice of licensed master social work and licensed clinical social work in New York. As a licensed professional, you are responsible for reviewing the scope of practice, including activities that are defined in law as beyond the boundaries of practice for an LMSW and LCSW. A licensee who practices beyond the authorized scope of practice could be charged with unprofessional conduct under the Education Law and Regents Rules.

A complete Works Cited list begins on page 26.

NetCE is recognized by the New York State Education Department's State Board for Mental Health Practitioners as an approved provider of continuing education for licensed mental health counselors. #MHC-0021.

This course is considered self-study by the New York State Board of Mental Health Counseling.

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This course is considered self-study by the New York State Board of Marriage and Family Therapy.

Designations of Credit

NetCE designates this enduring material for a maximum of 5 *AMA PRA Category 1 Credit(s)*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Successful completion of this CME activity, which includes participation in the evaluation component, enables the participant to earn up to 5 MOC points in the American Board of Internal Medicine's (ABIM) Maintenance of Certification (MOC) program. Participants will earn MOC points equivalent to the amount of CME credits claimed for the activity. It is the CME activity provider's responsibility to submit participant completion information to ACCME for the purpose of granting ABIM MOC credit. Completion of this course constitutes permission to share the completion data with ACCME.

Successful completion of this CME activity, which includes participation in the evaluation component, enables the learner to earn credit toward the CME and Self-Assessment requirements of the American Board of Surgery's Continuous Certification program. It is the CME activity provider's responsibility to submit learner completion information to ACCME for the purpose of granting ABS credit.

This activity has been approved for the American Board of Anesthesiology's® (ABA) requirements for Part II: Lifelong Learning and Self-Assessment of the American Board of Anesthesiology's (ABA) redesigned Maintenance of Certification in Anesthesiology Program® (MOCA®), known as MOCA 2.0®. Please consult the ABA website, www.theABA.org, for a list of all MOCA 2.0 requirements. Maintenance of Certification in Anesthesiology Program® and MOCA® are registered certification marks of the American Board of Anesthesiology®. MOCA 2.0® is a trademark of the American Board of Anesthesiology®.

This activity has been designated for 5 Lifelong Learning (Part II) credits for the American Board of Pathology Continuing Certification Program.

Through an agreement between the Accreditation Council for Continuing Medical Education and the Royal College of Physicians and Surgeons of Canada, medical practitioners participating in the Royal College MOC Program may record completion of accredited activities registered under the ACCME's "CME in Support of MOC" program in Section 3 of the Royal College's MOC Program.

NetCE designates this continuing education activity for 5 ANCC contact hours.

IPCE CREDIT™

This activity was planned by and for the healthcare team, and learners will receive 5 Interprofessional Continuing Education (IPCE) credits for learning and change.

NetCE designates this continuing education activity for 6 hours for Alabama nurses.

AACN Synergy CERP Category B.

Social workers completing this intermediate-to-advanced course receive 5 Clinical continuing education credits.

NetCE designates this continuing education activity for 2.5 NBCC clock hours.

Individual State Nursing Approvals

In addition to states that accept ANCC, NetCE is approved as a provider of continuing education in nursing by: Alabama, Provider #ABNP0353 (valid through 07/29/2025); Arkansas, Provider #50-2405; California, BRN Provider #CEP9784; California, LVN Provider #V10662; California, PT Provider #V10842; District of Columbia, Provider #50-2405; Florida, Provider #50-2405; Georgia, Provider #50-2405; Kentucky, Provider #7-0054 (valid through 12/31/2025); South Carolina, Provider #50-2405; West Virginia, RN and APRN Provider #50-2405.

Individual State Behavioral Health Approvals

In addition to states that accept ASWB, NetCE is approved as a provider of continuing education by the following state boards: Alabama State Board of Social Work Examiners, Provider #0515; Florida Board of Clinical Social Work, Marriage and Family Therapy and Mental Health, Provider #50-2405; Illinois Division of Professional Regulation for Social Workers, License #159.001094; Illinois Division of Professional Regulation for Licensed Professional and Clinical Counselors, License #197.000185; Illinois Division of Professional Regulation for Marriage and Family Therapists, License #168.000190.

Special Approvals

This activity is designed to comply with the requirements of California Assembly Bill 1195, Cultural and Linguistic Competency.

About the Sponsor

The purpose of NetCE is to provide challenging curricula to assist healthcare professionals to raise their levels of expertise while fulfilling their continuing education requirements, thereby improving the quality of healthcare.

Our contributing faculty members have taken care to ensure that the information and recommendations are accurate and compatible with the standards generally accepted at the time

Disclosure Statement

It is the policy of NetCE not to accept commercial support. Furthermore, commercial interests are prohibited from distributing or providing access to this activity to learners.

Course Objective

With the ever-increasing multicultural diversity in the landscape of the United States, culturally competent and sensitive practice is essential for practitioners. The purpose of this course is to increase clinicians' knowledge and awareness of the impact of culture on issues of death and dying in order to improve the provision of care and patients' quality of life.

Learning Objectives

Upon completion of this course, you should be able to:

1. Discuss the changing demographic trends that contribute to the United States' multicultural landscape.
2. Define the importance of cultural competence when working with patients and families around end-of-life issues.
3. Compare and contrast Western and non-Western sociocultural values surrounding end-of-life topics.
4. Describe cultural belief systems, values and norms for various racial and ethnic minority groups around death and dying issues including discussing death, attitudes towards death and dying, death rituals, grieving and bereavement, advance directives, palliative care, and other end-of-life issues.
5. Discuss culturally sensitive communication strategies when discussing death and dying and end-of-life issues with racial and ethnic minority patients and families, including the role of interpreters.
6. Identify best practice guidelines that reflect ethical cultural competence and sensitivity when working with racial and ethnic minority patients and families around issues related to the end of life.

E B
EVIDENCE-BASED PRACTICE RECOMMENDATION

Sections marked with this symbol include evidence-based practice recommendations. The level of evidence and/or strength of recommendation, as provided by the evidence-based source, are also included so you may determine the validity or relevance of the information. These sections may be used in conjunction with the course material for better application to your daily practice.

INTRODUCTION

When patients and their families are confronted with a terminal illness and issues of death and dying, it is undoubtedly a time of grief and stress. Although patients and families require support during this period, practitioners may be uncomfortable witnessing grief, as it may raise personal issues about their own mortality. This is further complicated when the issue of culture intersects with this highly emotional topic.

Culture is defined as the values and knowledge of groups in a society; it consists of approved behaviors, norms of conduct, and value systems as well as attitudes and beliefs that are passed from generation to generation within a group [1]. Culture is the lens by which individuals view the world and interact with others, the natural environment, and higher power(s) [2]. Although these definitions of culture are frequently presented as if there is a universal consensus, in practice, culture is a challenging concept to measure [8].

On the other hand, ethnicity is a marker of culture. Both cultural values and ethnicity influence death and dying and decisions regarding end-of-life issues [3].When there is a discrepancy between the linguistic and cultural value systems of the practitioner and patient, this increases the risk for cross-cultural miscommunication [4]. When communication styles, patterns, and differences are perceived to be irreconcilable, patients are more likely to become dissatisfied with services and to terminate treatment prematurely. This course will address how race, ethnicity, and culture impact issues of dying, including attitudes toward death, death rituals, grieving and bereavement, advance directives, and palliative care to ensure that culturally responsive care is provided at the end of life. In addition, best practices for interventions and service delivery will be framed within both a culturally relevant and ethical context.

THE UNITED STATES: A MULTICULTURAL LANDSCAPE

According to U.S. Census data, the minority population is growing each year. By 2044, more than half of the U.S. population will identify as a racial minority [10]. This group is also a young population. In 2019, the majority of Americans 16 years and younger are racial minorities [17]. By 2060, the minority population is expected to increase to 241 million, with the Hispanic population growing by 142%, the Asian population by 116%, and African American population by 50% [5].

Hawaii, New Mexico, California, the District of Columbia, and Texas are regions in the United States that consist of a "majority-minority," meaning that more than half of the areas' populations consist of individuals who are an ethnicity other than non-Hispanic white [6]. With the increase of immigration and the slower birth rate in white families, it is anticipated that the United States is rapidly moving toward becoming a majority minority [6]. In 2017, 58.6 million Americans identified as Hispanic, and this group accounted for more than half of the total growth in U.S. population between 2016 and 2017 [15].

It is important to remember that ethnic/racial minority groups are highly diverse, even among persons from the same area or group. One factor to take into consideration when assessing and caring for members of minority groups is the practice of religion, which is not always culturally bound. ***Table 1*** contains a brief overview of religious beliefs related to death and bereavement among the major religious groups in the United States. These religious customs may be practiced by any person, regardless of race or ethnicity.

AFRICAN AMERICANS

"African American" is a classification that serves as a descriptor; it has sociopolitical and self-identification ramifications. The U.S. Census Bureau defines African Americans or blacks as persons "having origins in any of the Black racial groups of Africa" [7].

According to the U.S. Census, African Americans number 48.2 million as of 2019, with the greatest concentration in New York (3.8 million) [20]. By 2060, it is projected they will comprise 17.9% of the U.S. population [11]. This group tends to be young; 30% of the African American population in the United States is younger than 18 years of age. In 2019, the median age for this group was 35 years [155]. In terms of educational attainment, 87.9% of African Americans 25 years of age or older had a high school diploma or completed college in 2019 [20]. Texas has the largest African American population, at 3.9 million [155].

ASIAN AMERICANS

As of 2019, 22.9 million Americans identified as Asian [156]. Between 2000 and 2019, Asians experienced the greatest growth compared with any other racial group at 81% [157]. In 2017, this group had the highest growth rate, at 3.0% [15]. The Chinese group represents the largest Asian subgroup in the United States, and it is projected that this population will grow to 35.7 million between 2015 and 2040 [110; 111]. In 2019, Chinese Americans (excluding Taiwanese Americans) numbered at 5.2 million [156]. They also have the highest educational attainment; 54.6% of Asians 25 years of age or older have a bachelor's degree or higher in 2019 [156].

"Asian" is a single term widely used to describe individuals who have kinship and identity ties to Asia, including the Far East, Southeast Asia, and the Indian subcontinent [12]. This encompasses countries such as China, Japan, Korea, Vietnam, Cambodia, Thailand, India, Pakistan, and the Philippines. Pacific Islander is often combined with Asian American in census data. The Pacific Islands include Hawaii, Guam, Samoa, Fiji, and many others [12]. There are more than 25 Asian/Pacific Islander groups, each with a different migration history and widely varying sociopolitical environments in their homelands [13].

AN OVERVIEW OF MAJOR RELIGIOUS IDEOLOGY AS IT RELATES TO DEATH AND BEREAVEMENT[a]

Topic	Buddhism	Catholicism	Hinduism	Islam	Judaism	Protestantism
Death	It is very important that everything be done to provide a quiet and calm environment for patients for whom death is imminent, as it is believed that calmness of mind at death translates to a better rebirth.	A priest should be called to give the Sacrament of the Sick if death is imminent. Last confession (Sacrament of Penance and Reconciliation) is made to a priest. Cremation is allowed; scattering of ashes is not.	A Hindu priest or Guru may be summoned for last rites. As the soul (jiva) is reincarnated until karmic absolution, death is seen as an opportunity to continue the spiritual journey.	Dying patients may request to face Mecca. Burial usually takes place as soon as possible, and there are special washing and shrouding procedures.	It is believed that one should not go into death alone; therefore, the dying individual will receive as much attention as possible. A confessional and shema (statement of faith) is read when death is imminent.	Traditions regarding death are also diverse. Some traditions require prayer and liturgies.
Bereavement	Prayers for an auspicious rebirth are said for the 49 days following an individual's death. Meditation on impermanence is also important.	The presence of a priest may be necessary for support during this time. Prayers for the deceased soul may be said, informally and/or formally (Mass and/or the Rosary).	Remorse for the deceased is believed to inhibit the spirit from leaving the body. Therefore, excessive mourning is discouraged, though not always avoided.	The head should be covered when speaking of the deceased. Continuous prayers are recited in the home for three days following an individual's death. Guilt is a common component of grieving.	Bereavement does not formally begin until the burial, after which there is generally a seven-day period of mourning (shiva).	Among Protestants, bereavement is less structured than in other religions. Each person should be individually assessed.

[a]This overview is meant only to give a simple, brief summary of general death/dying ideology of each religion. By no means are all of the rites or beliefs described practiced by all members of each religion; likewise, not all religious rites or beliefs are listed for each religion. As always, individualized assessment is encouraged.

Source: [152; 153; 154]

Table 1

Asian American groups have differing levels of acculturation, lengths of residency in the United States, languages, English-speaking proficiency, education attainment, socioeconomic statuses, and religions. For example, there are approximately 32 different languages spoken among Asian Americans, and within each Asian subgroup (e.g., Chinese), multiple dialects may be present [13; 14]. In 2019, California had the largest Asian American population, totaling 5.9 million [157].

HISPANICS/LATINOS

In 2019, the Hispanic population in the United States numbered 60.6 million [158]. The majority of the Hispanic population in the United States (63.3%) identify themselves as being of Mexican descent [21]. Approximately 27% of the U.S. Hispanic population identify as Puerto Rican, Cuban, Salvadoran, Dominican, Guatemalan, Colombian, Honduran, Ecuadorian, or Peruvian [16].

In 2019, the Hispanic population comprised 18% of the U.S. population [159]. As such, they are the largest ethnic minority group in the United States. By 2060, Hispanics are expected to represent 31% of the U.S. population [8]. They are also a young group, with a median age of 29.8 years [158]. In 2019, the three states with the largest Hispanic population growth were Texas (2 million), California (1.5 million), and Florida (1.4 million); these three states have the largest Hispanic populations overall [159].

NATIVE AMERICANS

The Native American population is extremely diverse. According to the U.S. Census, the terms "Native American," "American Indian," or "Alaskan Native" refer to individuals who identify themselves with tribal attachment to indigenous groups of North and South America [19]. In the United States, there are 574 federally recognized tribal governments and 324 federally recognized reservations [160].

In 2019, it was reported that there were 6.9 million Native Americans in the United States, which is approximately 2% of the U.S. population [160]. By 2060, this number is projected to increase to 10.1 million, or 2.5% of the total population [160].

In general, this group is young, with a median age of 31 years, compared with the general median age of 37.9 years [112]. As of 2018, the states with the greatest number of residents identifying as Native American are Alaska, Oklahoma, New Mexico, South Dakota, and Montana [113]. In 2016, this group had the highest poverty rate (26.2%) of any racial/ethnic group [112].

CULTURAL COMPETENCE AT THE END OF LIFE

Although there is no universally agreed upon definition of cultural competency, three main themes are generally included in any discussion of the topic: cultural sensitivity, cultural knowledge, and cultural skills [2]. The goal of cultural competency is to reduce the differences between the institutional cultural norms of service delivery agents and the belief systems of patients from diverse cultural groups. Ultimately, this will help to minimize the disparities that exist in the current mental health and healthcare systems [22].

E B
EVIDENCE-BASED PRACTICE RECOMMENDATION

The Institute for Clinical Systems Improvement asserts that palliative care providers should evaluate their services, policies, and procedures to maximize cultural and linguistic accessibility and responsiveness to changing multicultural populations.

(https://www.icsi.org/wp-content/uploads/2020/01/PalliativeCare_6th-Ed_2020_v2.pdf. Last accessed August 26, 2021.)

Strength of Recommendation/Level of Evidence: Guideline (Expert opinion)

Cultural sensitivity consists of promoting trust and mutual respect for cultural differences between providers and patients [2]. In end-of-life care, an understanding of cultural differences in beliefs about grieving is necessary. In Western culture, grieving is expected to be time-limited, and extended grieving can be considered pathologic [23]. However, in other cultures, extended periods of grieving are socially sanctioned. For example, Egyptian parents who have lost a child are allowed a grieving period that lasts up to seven years [24]. In terms of program planning, cultural sensitivity can be expressed in the design and implementation of physical layouts of space. For example, some cultures (e.g., Native American) revolve around extended family and the community. The physical environment in which a patient receives care should take into account this collectivistic orientation. Rooms large enough to accommodate the many extended family members who come to visit would be needed [25]. In Muslim culture, a patient and his/her family members might request that the patient's bed face Mecca [114]. Many Hmongs practice rituals, such as using charms to ward off evil spirits [161].

Cultural knowledge is an important component of cultural competency, as practitioners should have a foundational understanding of different cultural worldviews, beliefs systems, and practices [2]. The United States and other Western countries, for example, are guided by cultural values of individualism, which focus on autonomy and independence. In the healthcare system, practitioners emphasize that patients have the right to make their own decisions regarding care. Consequently, informed consent, whereby practitioners will convey information to individuals so that they can make an informed decision about their care, is the backbone of health decision-making processes in the United States [26]. However, other cultural groups have a more collectivist orientation, which emphasizes group decision making with the family rather than individual autonomy [26; 162]. Key family decisions about treatment and lifesaving measures are discussed by the family, which decides together what will be done [163]. Practitioners who do not understand this may feel that a family is undermining the patient's autonomy or that the patient is overly dependent.

Finally, the ability to integrate and apply cultural sensitivity and knowledge in one's day-to-day practice with patients is referred to as cultural skill [2]. Cultural groups adhere to culturally laden beliefs about death rituals, death symbols, language, gender roles, advanced care planning, end-of-life directives, and bereavement and grief. As a result, a provider's level of cultural competence will influence how he or she interacts with patients and family members during the end of life, ultimately influencing how patients and families perceive the end-of-life experience [135]. In traditional Asian families, for example, the eldest son may be designated to make key health and end-of-life decisions [114]. Various cultural groups will have specific norms about the expression of emotion during funerals. White Protestant individuals, for example, may value stoicism, while the Chinese equate the amount of wailing to the amount of respect paid to the deceased [27]. Crying that involves shaking of the body is considered cathartic and a normal reaction in some cultures [28].

Conveying bad news is another culturally specific practice. In Western cultures, truth telling and honesty are generally highly valued and are considered essential parts of the informed consent process. However, some Asian patients may consider a direct statement conveying bad news (e.g., a poor prognosis) to be rude and inappropriate [135]. For these patients, a more indirect approach using euphemisms may be preferred [29]. Outside of the United States, practitioners often conceal serious diagnoses because disclosure is viewed as disrespectful and harmful to the patient [30]. Practitioners who are not aware of these cultural differences may inadvertently label behaviors as problematic or pathologic.

For many cultural groups, dying is viewed as a process, and within this process, there are social events, preparations, and many relationships involved. Family members respond to these events dynamically. Consequently, healthcare providers should understand that the wishes of the patient and family may change or evolve [164]. Ultimately, cultural competence in the area of illness and death involves adopting a holistic and phenomenologic perspective, which asserts that "the subjective experience of illness, rather than physiologic descriptions of disease, should take priority. If care is to be 'person-centered,' it is necessary to enter the patient's world, to see the illness through the patient's eyes. A phenomenologic approach which attempts to understand the experience of illness 'from the inside' is therefore highly appropriate" [115].

It is also important to consider intersectionality in discussions of cultural competence. Individuals do not belong in one category in terms of their identity. Often, patients have overlapping identities (e.g., sex/gender, socioeconomic status, religion, class, sexual orientation, racial/ethnic minority group). This contributes to discrimination and marginalization, which influences how one experiences death and dying [136]. Some experts assert that the word "competence" in cultural competence is a misnomer, because it implies that providers can obtain a "rational mastery and application of knowledge" [165]. End-of-life care planning is complex, and cultural competence entails being reflective and accessing one's intuition.

CULTURAL ORIENTATIONS AND HEALTH DECISION MAKING

Giger and Davidhizar's Transcultural Assessment Model is often used to provide a framework to conceptualize the role of cultural orientations and belief systems in shaping health decision making. The Model identifies six cultural phenomena that practitioners must understand and incorporate into practice when working with culturally diverse patients and families. These six domains are [31]:

- Communication
- Space
- Biologic variations
- Time
- Environmental control
- Social organizations

Issues may arise in any or all of these categories. This is particularly true when addressing a complex issue such as end-of-life care.

COMMUNICATION

Communication, the process of sending a message from one party to another, consists of both verbal and nonverbal components. Verbal and nonverbal communications are embedded within the culture of the parties disseminating the information and within the culture of the parties receiving the information. Communication is complex and multilayered because it involves unstated, implicit rules regarding a variety of factors, including physical distance between parties, tone of voice, acceptable topics of discussion, physical contact, and amount of eye contact [32]. Each of these variables is influenced by the perception of the level of formality/informality of the situation. Frequently, misunderstandings occur because the decoding and interpretation of nonverbal cues are not accurate.

The verbal component of communication is just as complicated. Certainly, similarity in language shared by both parties enhances communication, but assuming that both parties in a conversation speak the same language, how the information is interpreted is still influenced by a host of factors. Linguists have posited that approximately 14,000 different meanings and interpretations can be extracted from the 500 most common English words [33]. Consequently, practitioners must be aware of the different communication styles held by diverse ethnic minority patients, as the clinical communication process is the primary vehicle by which problems and solutions are identified and conveyed [34].

Styles of communication can be classified from high- to low-context [35]. High-context cultures rely on shared experience, implicit messages, nonverbal cues, and the relationship between the two parties to disseminate information [33]. Members of these cultural groups tend to listen with their eyes and focus on how something was said or conveyed [32; 35]. On the other hand, low-context cultures rely on verbal communication, or what is explicitly stated in the conversation [33]. Consequently, low-context communicators listen with their ears and focus on what is being said [32; 35]. Western culture, including the United States, can be classified as a low-context culture. On the other hand, groups from collectivistic cultures, such as Asian/Pacific Islanders, Hispanics, Native Americans, and African Americans, are considered high-context [35]. In one study, older immigrant Korean elders reported minimal communication with a healthcare provider about end-of-life issues [116]. This trend may be because practitioners assume that Korean and other Asian elders are not comfortable talking about death and dying, based on the cultural belief that discussing death openly invites bad events [166]. Asian elders tend not to explicitly raise the topic; practitioners should watch for nonverbal cues and resist ascribing this belief to all members of the Asian community. Clearly, adherence to cultural values influences communication styles. Cross-cultural communication is by no means simple, and there is no set of rules by which to abide. Instead, promoting culturally sensitive communication is an art that requires practitioners to self-reflect, be self-aware, and be willing to learn. Therefore, as practitioners become skilled in noticing nonverbal behaviors and how they relate to their own behaviors and emotions, they will be more able to understand their own level of discomfort and comprehend behavior from a cultural perspective [32].

SPACE

The amount of social space or physical distance between two communicating parties is culturally charged as well. Depending upon the social context, Westerners tend to maintain a distance of about 3 feet, or an arm's length, in conversations [33]. In a public setting, where both parties are engaged in a neutral, nonpersonal topic, Westerners will feel encroached upon and uncomfortable if an individual maintains a closer conversational distance. However, in other cultures, such as Latino and Middle Eastern, a closer distance would be the norm [33]. Asians tend to prefer more space between the two conversational parties until they have developed a relationship. Chung recommends that in a clinical setting, the practitioner allow Asian patients to set the tone and social distance [36]. The practitioner can sit first and permit the patient to select where he/she would like to sit.

BIOLOGIC VARIATIONS

Biologic variations are differences in food preferences, physical development, and physical appearance. Cultural groups have unique beliefs about food and its place in society and one's life. For example, the concepts of the yin and yang and "hot" and "cold" are very common among Asian, Indian, Muslim, and some Latino cultures [37]. Foods are identified as "cold" or "hot," with the goal of balancing one's consumption of each type; too much of one can trigger illness. Similarly, medications may be considered "hot" or "cold." If an illness is believed to have been caused by "hot" foods or energy, the treatment would be "cold." Some patients who are reluctant to follow a course of treatment may be concerned regarding this balance. Practitioners should explore the underlying reason for this reluctance rather than simply categorizing a patient as "resistant" or "difficult."

TIME

Time and time orientations, or how individuals view the past, present, and future, are also culturally laden. Americans tend to have a monochronic orientation, meaning they prefer to do one thing at a time and are focused on the efficient management of time [36]. However, other groups, such as Native Americans and Hispanics, are more present-oriented, viewing time as rhythmic and circular [38; 39]. Some cultural groups are also polychronic, preferring to work on multiple activities simultaneously. Depending upon a group's orientation, some may believe that it is more important to be attuned with nature and go with the "flow" than to follow a schedule [36]. These time orientations have implications for health decision making and the practitioner/patient relationship. Members of cultural groups that are more present-oriented will not necessarily adhere to time tables and appointments and may find it less amenable to plan advance directives [39]. This may be perceived as lackadaisical or rude by those who are not familiar with the group's cultural norms about time [37].

ENVIRONMENTAL CONTROL

Environmental control refers to one's perceived ability to control external factors in the environment [37]. In many Western countries, the cultural principles of individualism and the Protestant work ethic pervade. In these cultures, the belief in personal responsibility is vital; one is expected to take control of destiny and exert control over the external environment. By extension, Western medicine focuses on curative and preventive medicine, which again emphasizes autonomy and control. However, some groups have a more fatalistic view, attributing outcomes to chance, destiny, or fate [37]. These groups have externalizing explanations of disease etiologies, focusing on possible causes that are rooted in either the environment or specific circumstances. In cultural groups with externalizing explanatory systems, disease may be attributed to an individual who is believed to hold a grudge or an angry ancestor.

SOCIAL ORGANIZATION

The networks and groups (e.g., family, church, tribes, community, religion) with which individuals identify and derive their identity, social support, and frames of reference are considered a culture's social organization. These social organizations play an important role in individuals' decision making and health behaviors. For example, in Hispanic families, the cultural values of *familismo* (emphasizing the family over the individual), *respeto* (respect for older persons), and *dignidad* (maintaining dignity and not asking for help) impact family members' decisions regarding the use of nursing homes and hospice care [40]. Respect for the patient's religious and spiritual beliefs is also vital. For example, Muslim patients and their families may require prayer mats in the rooms. Care of female patients in certain racial/ethnic minority groups should take into consideration the gender of the practitioner and minimize unnecessary touching [167].

Traditional Asian beliefs and values are often centered around Confucian thought, which focuses on harmony, unity, and family [36]. Children are expected to obey their parents and demonstrate filial piety and to repay their parents for all the sacrifices they have made for them. Members of Asian families that emphasize the role of filial piety may feel that the family should provide the care to the patient [135]. Asai and Kameoka further argue that it may not necessarily be filial piety that influences the Japanese to provide caregiving, but rather the cultural value of *sekentei* [41]. *Sekentei* refers to social dignity, reputation, and social appearance in public. It taps into the notion of individuals behaving in a certain way in order to influence the public's perception of them. In terms of caregiving, *sekentei* comes into play because individuals are concerned about what others may think of them if they do not provide caregiving [41].

DEATH AND DYING: WESTERN MEANINGS

Western notions of death, dying, and grief have been shaped by the Western biomedical model and Sigmund Freud's theoretical paradigm outlined in the publication *Mourning and Melancholia* [42]. In general, Western traditions believe that life begins and ends, and death is primarily viewed as the cessation of the individual's bodily organs [117]. In Western cultures, death is generally considered a topic that should not be discussed. When death occurs, particularly for those who have been ill, members of this culture tend to assume that the biomedical model has failed. Some experts have referred to this Western concept as "death denying" [137; 138]. Overall, in Western culture, individuals tend to remove or detach themselves from the death and dying process [168].

When it comes to grief, Freud distinguished between normal and pathologic grief, defining pathologic grief as the inability to "decathect" from the relationship with the deceased. Freud believed individuals who could detach themselves and move on were experiencing "normal" grief. According to this paradigm, the "normal" grief period is an intensely emotional time, but it is time-limited, with an expectation that the bereaved should return to normal functioning as quickly as possible [23]. If an individual is unable to detach in an "acceptable" period of time, then pathologic symptoms will emerge. Freud's theoretical assumptions were based on Western cultural beliefs that mourning is a private affair and that death is final [43]. If an individual experiences pathologic grief, according to this definition, grief work with a mental health professional may be undertaken. However, in Western cultures, individuals are generally expected to "work through" their grief alone [23].

In the United States, there are generally no post-funeral rituals to facilitate grieving or assist surviving family members and friends to reintegrate into life without the deceased [44]. There are concrete tasks that must be completed, such as filing life insurance and social security claims, closing bank accounts, and executing wills, that keep family members busy, but they do not allow for advancement of the grief process [44]. As a result, surviving family members may struggle with how to express or experience grief. In Western cultures, public displays of grief after a funeral signal pathologic grief and make others uncomfortable [44]. Grief is to be regulated by oneself, and if this is not possible, particularly over a period of time, the grieving individual is expected to obtain help through a professional or self-help group [118; 138]. Ultimately, grief is meant to be worked in a limited amount of time [118]. This is manifested in terms of the amount of leave time (e.g., three days) a workplace allows for bereavement [137].

In the United States and Northern Europe, mourning practices may have shifted during World War I [45]. Prior to this, during the Victorian period, there were prolonged and complex mourning practices, some of which lasted for more than two years. However, because of the high death toll in the war, it has been posited that society psychologically distanced itself from the mourning and grieving process. Instead of expending time and effort with death and mourning rituals, energy was expended on working and patriotic efforts [44]. This may have formed the foundation of modern Western views of death and dying.

ISSUES OF DEATH AND DYING: CULTURAL CONSIDERATIONS

It is important to remember that the following discussion about the role of culture in issues related to death and dying is not prescriptive. It is not meant to be applied universally across racial and ethnic minority groups, as there is a tremendous amount of diversity within each of these groups. Age, gender, educational level, age at immigration, immigration status, socioeconomic status, and acculturation level all contribute to this rich heterogeneity.

DELIVERING BAD NEWS AND DISCUSSING END-OF-LIFE ISSUES

Bad news has been defined as any information that would negatively affect their views of the future [119]. Unfortunately, the delivery of bad news and end-of-life planning cannot be avoided. When necessary, adhering to culturally sensitive practice can ensure patient satisfaction, as truth telling is culturally influenced. As discussed, the Western biomedical model emphasizes the full disclosure of information to allow for informed decisions [29]. This model assumes that patient autonomy is paramount and that patients want to hear a realistic assessment of their prognosis, which may not be true in all cultures [29; 139; 166]. For example, some Native American groups, such as the Navajos, believe that language can dictate reality and therefore outcomes [46]. Traditional Japanese cultural beliefs maintain that language has a soul of its own, referred to as *kotodama*, a term meaning word and soul [47]. In these cases, language is believed to be so powerful that it can dictate the course of events [47]. This is also the case in some Pacific Islander groups (e.g., Maori) who believe that words can transform the thought into reality [120]. Some who adhere to this belief may avoid talking about death and serious illnesses [48]. Others may prefer that communication be more indirect, relying on nonverbal means, inferences, and euphemisms [29]. These patients may want information but prefer that it be delivered in an indirect manner [166].

The amount of family participation is another consideration in the disclosure of bad news, particularly in collectivistic cultures. In some collectivistic cultures, the family can supersede the individual's decisions and preferences [121]. Collectivistic cultures emphasize the importance of other people and the community versus personal autonomy [49]. In one qualitative study comparing non-Hispanic whites' and Hispanics' perspectives regarding hospice care, death, and terminal prognoses, the cultural value of familism appeared to play a dominant role. Among the Hispanic participants, family members felt that it was their duty to protect the patient as well as other family members [50]. In some cultures (Hispanic/Latino, Asian Indian), telling the truth to a family member is frowned upon because they believe this can destroy a person's hope, expediting death [140; 141]. This was not as common a theme among white participants. In another qualitative study that focused on the perspectives of oncologists working with immigrant families and patients, oncologists stated that the families were the biggest barrier to "truthful" communication [121]. Some participants indicated that family members would attempt to "ambush" or "catch" the doctor before they had a chance to speak to the patient [121]. Similarly, in Chinese cultures, especially those adhering to Confucian principles, strict truth-telling goes against the cultural value of striving toward family harmony and the belief that the family knows best [140]. In some cases, family members may serve as interpreters. When this occurs, family members are put in the position of delivering bad news. Some providers choose family interpreters because they feel that family will be in a better position of knowing the patient's needs [169]. However, it raises serious ethical and professionals issues.

Practitioners may feel torn between upholding Western ethics of autonomy and respecting the desires of the family members and being culturally sensitive [121]. Again, keep in mind that the cultural values underpinning the concepts of patient autonomy and collectivism will guide decisions regarding the delivery of bad news and discussions of death and dying. Assumptions should not be made based on a dichotomous categorization.

BELIEFS REGARDING DEATH

All cultures attribute specific meanings and significance to death and dying, and these meanings are influenced by the group's religious, philosophical, and cultural belief systems. Although it is beyond the scope of this course to provide a comprehensive discussion of all of the beliefs of racial and ethnic minority groups, this section will provide a very broad overview based on a sampling of various cultural groups.

Many Hispanic cultures normalize death as part of the course of life and part of God's will (fatalism) [142]. In Mexican culture, death is often portrayed in art, literature, and history, leading some to claim that Mexicans have a "cultural familiarity with death" [51]. In Hispanic cultures, *familismo* plays a prominent role in the remaining life of the patient. All individuals who are considered family members, including children, have a place in the dying process [122]. Family members often come from afar and drop their day-to-day responsibilities to be with the patient [122].

For African Americans, there is tremendous diversity in views about death depending upon individuals' religious affiliations. For example, African Americans with a Baptist tradition generally believe in heaven as an afterlife where the deceased will see God [51]. Some African Americans believe cremation inhibits entry into heaven [170]. A growing number of African Americans are Muslim, and Muslim tradition emphasizes spiritual progression in the afterlife.

The concept of death for Native Americans is defined by beliefs regarding balance and harmony. In many Native American traditions, the worlds of the living and the dead are not separate but are believed to exist simultaneously. The bodies of the deceased help the earth to produce new life, thereby extending the cycle of life [52]. In a qualitative study with 27 participants from the Creek tribe, the individuals described transitions as being circular—not beginnings or finalities [52]. According to this belief system, death is an essential part of the cycle of life. However, not all Native American groups hold these same beliefs [53].

Chinese views about death are influenced by Confucianism, Taoism, traditional Chinese medicine, and Buddhism [54]. Similarly, Japanese views of death are influenced by Shintoism, Confucianism, and Buddhism. In general, death is considered a taboo topic and to talk about death is to potentially bring about misfortune [27]. In Chinese and Japanese cultures, the soul is believed to remain in the body after death [123]. This belief informs various traditions surrounding death. For example, in Japan, after the physician officially declares the death, the nurses clean the body and apply makeup to the face of the deceased. A "seeing-off ceremony" involving the physicians, nurses, and family members is then done during the transfer of the body to the mortuary [123]. Similarly, Hmongs believe that the soul of the deceased individual requires help transitioning to the next life. Shamans, funeral singers, and soul guides may be invited to assist in this endeavor [163].

The Chinese adhere to specific rules regarding treatment of the dead that reflect back to principles of propriety and filial piety. This includes ancestor worship, which consists of surviving family members honoring the dead by performing certain rituals (e.g., bringing and burning food and paper money at gravesites during an annual holiday to commemorate the dead) [27]. Ancestor worship rituals perpetuate the bond between the living and the dead [54]. Some Chinese individuals adhere to "memorial piety," or demonstration of remembrance through ancestor worship [171]. Not adhering to these traditions can cause displeasure among the ancestors and result in bad luck. This belief is partially an extension of the Chinese belief in evil spirits or *qi* (i.e., the flow of energy, in this case bad energy) [55]. In many Asian cultures, the ghosts of the dead can cause bad luck, ill health, or even death, as early deaths are considered the result of evil or angered spirits [55]. Widows are considered bad luck, and during the first year of mourning, they are expected not to join in weddings, birthdays, and other celebrations [124].

THE NOTION OF A GOOD DEATH

The concept of a good death is prevalent in many cultures and is reflective of societal views about both a good life and a good death [172]. These beliefs influence treatment and end-of-life care decisions. From a Western perspective, patients who die with dignity, pain-free, and with an opportunity to communicate openly with family members and make decisions regarding end-of-life care are believed to have had a good death [56; 125]. This is the underlying notion of Western palliative care [172]. In one study, older patients defined a good death as having family and friends by their bedside and having advance knowledge of their imminent death [143]. This conception of a "good death," in which one controls the activities and environment, is congruent with Western values of individualism [144].

Although many racial and ethnic minority groups share similar definitions to Western views of a good death, there are some cultural variations. For African Americans, the concept of a good death is dependent on the amount of control an individual has over his/her dying process and the amount of closure in his/her life [57]. Spirituality and religion are paramount in many African Americans' lives, and African American focus group participants stated that the deceased having a relationship with their Lord is a defining dimension of a good death [126]. In a systematic review, African Americans and Hispanics identified spiritual support as key to a good death [164]. Koreans have a specific term, ho sang, meaning good death or blessed death, used to describe death following a long and a prosperous life [58]. One study of older Korean individuals found that they defined a good death as having the following components [59; 173]:

- Having their children outlive them
- Dying with their children around them
- Having lived life without being a burden to their children
- Fulfilling their parental duties
- Dying without pain
- Completing the natural order of life
- Being prepared for death

These components clearly reflect the Asian cultural values of filial piety and family. In a qualitative study of Chinese cancer patients in Hong Kong, participants defined a good death to include positive relationships with family members, control of one's life and symptoms/pain, and acceptance and awareness of death [60]. Additional factors that contribute to a good death in Chinese cultures include good relationships with family, independence, positive mental status, and physical and environmental comfort prior to death [125].

DEATH OF A CHILD

The death of a child, regardless of how old, is a tremendous crisis to families. It can bring into question the order of life and trigger unique family dynamics [126]. The challenge to processing this grief lies in constructing meaning of the traumatic event and integrating the loss. Again, it is impossible to provide a comprehensive cultural analysis, as variations exist within cultural groups.

The Chinese have a saying that black hair should not precede white hair. In other words, the death of a child should not occur before the death of a parent, because, among other reasons, this would prevent the child from fulfilling obligations of filial piety [145]. Similarly, the Korean culture has an adage that when a parent or spouse dies, one buries them underground, but when a child dies, they are buried in the loved one's heart [61]. In many cultures, the death of a child is viewed as bad luck caused by evil spirits, perhaps as punishment for some past misdeed [27; 55]. Many traditional Chinese families will not hold a burial or funeral for children in part because the death of a child is considered a bad death (i.e., shameful) and because the hierarchal family roles dictate deceased children should not be worshipped by adult living family members [62; 124]. If one is held, it is not elaborate, and parents and grandparents are not expected to attend because their presence could bring about more misfortunes [62]. In these cases, only children, accompanied by their parents to watch and supervise them, will be present; it is not customary for elders to pay their respects to children [63]. In some cases, children will precede the coffin while the older generation follows, with the parents at the end [63]. Cultural norms dictate that parents should not overly mourn the death of their children, as this goes against the hierarchal order [145].

In Puerto Rican families, a child who dies is dressed in white as a symbol of innocence [170]. For Catholic families, a novena (a type of worship held over nine days with special prayers asking for forgiveness) may not be needed because the child is considered free of sin [170]. Attendants at these services wear lighter colors rather than black [170]. In Native American cultures, some tribes do not name an infant until after his/her first year, in part due to historically high infant mortality rates. In other traditions, the name of the child may be changed to confuse the spirits, preventing them from making the child ill. Many Native Americans believe that when an infant or young child dies, the child will be reincarnated in another family through another birth [38].

DEATH RITUALS

To many people, death is considered a major life event, in some cases the last, and is marked as such by rites of passage. A rite of passage consists of a series of cultural practices that help transition a group or an individual from one phase of life to another [44]. Rituals are practiced as a group or as an individual, and they often have strong symbolic meaning [44]. Neimeyer, Prigerson, and Davies state that rituals "serve both integrative and regulatory goals by providing a structure for the emotional chaos of grief, conferring a symbolic order on events, and facilitating the construction of shared meanings among members of the family, community, or even nation" [64]. During a time of crisis and grief, rituals can be healing and provide structure to chaos [174]. Rituals help to acknowledge a change in status, serve as a mechanism to deal with feelings of powerlessness, and maintain a connection to the person who has passed [146; 147; 174; 175]. These behaviors are not always rational, as they involve a high degree of emotion and sensory stimulation [175]. Rituals also bring people together to mourn and enhance relationships [148]. Five factors common to funerals or death rituals across all cultures are [127]:

- Symbols that convey culture, trigger emotions, and help recognize the deceased
- Gathered community to offer support to those left behind
- Ritual action to bring everyone together but also help them to move on with their loss
- Connection to heritage
- Transition of the corpse

Death rituals have order and meaning, but there are other components of these rituals that may be confusing and difficult to explain [63]. It is this incomprehensible dimension that allows for expressions of grief that are consistent with the group's cultural belief system. Understanding death rituals of various cultural groups provides a glimpse into how groups give meaning to life and death [65]. Rituals also provide insight regarding the role of surviving family members in relation to their family, community, and the deceased. Death rituals assist mourners to make the transition to their new identity (e.g., husband to widower) [175]. All of this is influenced by cultural value and belief systems and religion [65].

In Hispanic culture, death rituals are influenced by Catholicism and cultural norms. There is a preference for burials versus cremation, novenas (religious devotion through prayer, usually for nine days), lighting of candles for the deceased for a period of time, and a Mass said for the deceased during the first year and annually thereafter [51; 66; 176]. Elaborate wakes and large extended family gatherings are common, with food and many family members [176]. Loud wailing is common among the women, but men remain more stoic, conforming to Hispanic cultural values of *machismo* [51; 66].

African American death rituals vary widely as a function of religious affiliation and geographic region. In general, the funeral often involves a large gathering of family and friends to pay respect to the deceased. They are also viewed as "home-going" celebrations, and therefore, the mood is not necessarily somber [177]. In the past, African Americans in the South had a viewing of the deceased in the house before the funeral, but this has largely been abandoned [51]. In some cases, "flower girls" (actually adult women) may walk with the pallbearers during the funeral procession. In Afro-Caribbean cultures, open caskets are common. Laying of hands and touching are common gestures of communicating one's grief [146]. Food is served and memories are shared [146]. In Haiti, funeral and death rituals have elements of Catholicism and Vodou, stemming from Haitian history and West African diaspora resulting from slavery [177].

Death rituals among Native American tribes are also diverse. In one study, 27 Muscogee Creeks were interviewed about their death ritual practices [67]. Sixteen of the participants indicated that the body of the deceased was not left alone until the burial, because the spirit is believed to remain on Earth for four days. During this four-day period, it is believed that the deceased person's spirit visits the different places he/she lived on earth. Family members and friends may leave favorite items and food in the casket, so the spirit will be well provided for during the journey to the afterlife. Other Native American groups place the deceased's belongings in the casket or destroy them, so the spirit does not return looking for his/her things [38].

In Chinese culture, it is important that the soul of the deceased travels safely, with adequate provisions for the afterlife. After the funeral, it is common to light incense, burn paper money, and have a whole chicken and wine placed at the gravesite [145]. It is believed that the deceased should be provided for, which reflects cultural beliefs about filial piety [27]. After the burial, a meal is offered and attendees are invited to partake as a token of the family's appreciation [148]. The Chinese emphasize the importance of following the customs of death rituals properly as a reflection of one's respect for a parent or elderly relative [68]. The Qingming Festival is a holiday in the spring during which families visit cemeteries to sweep the tombs of their family members, bring food and flowers, and burn incense [178].

Similarly, the Japanese bring "incense money" (*koden*) to funerals [69]. Survivors place money in an envelope labeled with their name, and the family of the deceased keeps a careful record of who brings *koden*. Approximately 49 days later, a gift is reciprocated to the donor. In this way, social networks and bonds are reinforced and family members have a clear sense of communal attachment [69]. Throughout the year, rituals are performed in order to connect with the deceased and to provide comfort to the living, particularly the elderly [149].

For Asian Indian Hindus, cremation is common; burials are contrary to cultural belief systems. Hindu adults who pass away are cremated, and this process is considered necessary purification. Hindu children have not fully developed and have not become impure, and therefore, they do not need to undergo the purification rites after death [70]. Traditionally, male relatives will attend the cremation, and the oldest son will light the fire for the cremation ritual. (Women are not permitted to attend.) The mourning period generally lasts 10 to 16 days. During this time, the family is perceived to be tainted, and friends and distant relatives do not visit [70].

MOURNING, GRIEF, AND BEREAVEMENT

Mourning has been defined as specific cultural norms, behaviors, or practices associated with the sorrow or grief experienced by family members and friends of the deceased, while grief is the affective and cognitive experience resulting from loss [71]. The period of mourning and grief following a loss is referred to as bereavement, and this period varies from individual to individual and from culture to culture [72].

As described, Western culture views grief and bereavement as time-limited in part because death is viewed as a finality. According to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), two weeks are given before a diagnosis of depression may be made [138]. However, in some cultures, there continues to be a bond between the deceased and family members. When a culture has an extended death ritual, it conveys the belief that the bereavement process is not easy or quick [44]. Rather than relying solely on a model that espouses "closure" and "moving on," an alternative model of mourning that emphasizes a continuing bond with the deceased may be more appropriate [73]. Instead of letting go of the representation, memories, and/or events associated with the deceased, family members may continue to integrate, identify with, and create bonds with objects that serve as a representation of the deceased [74; 178]. This process is not time-limited nor is it considered pathologic. This model appears to be more consistent with cultural norms among many racial and ethnic minority groups.

In Asian cultures, ancestor worship helps to maintain a bond with the deceased, and family members will regularly burn offerings to the deceased. In the Chinese tradition of *han san* (which translates to "walking the mountain"), family members visit the cemetery annually and bring food and paper money to continue providing for the deceased in the afterlife [27]. In a study of 10 Chinese parents who had lost a child, the majority indicated they kept a photo of their deceased child in their home to share memories with friends and family members; some burned incense near the photo [62].

Many South Asian Muslims participate in elaborate death ritual over three days that involves bathing the body, reciting the Quran, holding a funeral, and following specific procedures and processes for the burial [128]. There are also specific holidays, such as Ramadan and Eid, during which the deceased are remembered [128].

African Americans also emphasize an ongoing connectedness or bond with the deceased despite the end of their physical presence [68]. In a study comparing African American and white college students who had experienced bereavement, African Americans reported a closer bond with the deceased compared with their white counterparts [68]. The African American students reported they sought out certain activities to remind themselves of the deceased or had conversations with the deceased.

Continuing the bonds with the deceased is also a part of Hispanic/Latino cultures. Storytelling, keepsakes, religious rituals, and pictures may be used to remember lost loved ones [75]. Cooking favorite food items of the deceased on the Día de los Muertos (the Day of the Dead) and using a certain flower to tempt the spirit of the deceased back home are cultural practices designed to stay connected with the deceased.

It is important not to adhere to cultural generalizations. While many collectivistic cultures emphasize the continuation of bonds with the deceased, there are subgroups (e.g., Wahabi Muslims) who argue that death is part of God's will [128]. Consequently, this subgroup discourages ritualized mourning. Some argue that this tradition has less to do with cultural beliefs and is more due to economic pressures [128].

Expressions of grief and bereavement also vary from culture to culture. In Vietnamese culture, the vocal expression of grief and the number of mourners is equated with the level of importance of the deceased [76]. Because of this, mourners may be hired to join in funeral processions. Instead of black, white is the color of death in the Vietnamese culture. Close family members wear simple white apparel, and guests may be given white headbands to wear [76]. In Chinese culture, the bereaved wear mourning apparel of different colors, signifying the relationship to the deceased [148]. However, public expression of emotion (including crying) is taboo in Chinese culture, especially among Taiwanese communities. In these groups, suppressing emotions is believed to facilitate the transition to the afterlife, as the deceased will not feel burdened to remain with the living [179]. During the grieving period, other happy celebrations, such as weddings and birthdays, are avoided [62].

In African American culture, explicit outward demonstrations of emotion are common, particularly among women and children who identify as Southern Baptists or are recent African immigrants [77]. This practice has been called "falling out" and is a culture-bound syndrome recognized in the DSM-5 as a dissociative experience involving fainting and emotional distress [77].

In some cultures, grieving is not as public. Many Native American and aboriginal people view outward expressions of grief to be inappropriate. Some may consult with traditional healers, while others use sharing circles [78]. In the United States, non-Hispanic whites tend to grieve with less display of emotion [129].

ADVANCE DIRECTIVES

Advance directives, living wills, and other documents detailing an individual's wishes regarding care are deliberate processes designed to allow the individual to control end-of-life decisions, such as life-sustaining interventions, or to designate a proxy to make these decisions in the event of incapacitation [79]. In the United States, the Patient Self-Determination Act (PSDA) requires that hospitals, nursing homes, and other healthcare facilities provide information about advance directives to adult patients [80]. The goal of the PSDA is to increase individuals' control and autonomy in making informed decisions and obtaining the care they desire [80].

Western institutions, such as the PSDA and advance directives, are based on the beliefs that autonomy and individualism are desirable, truth telling is important, and individuals should have control over their deaths [80]. However, these assumptions are not universally accepted and may be culturally dissonant with the belief systems of non-Western groups. This is reflected in the different practices worldwide. In countries such as India, advance directives are not recognized as valid legal documents, while in other countries, like Turkey, advance directives are formally recognized but not uniformly followed [79]. In some cultures, avoidance of talk about death makes advance directive use impractical, as conversations about advance planning could be considered a personal affront or an assault on the person's well-being [79; 81]. Instead, language should promote harmony and positivity. For some Native American groups, advance directives are considered a violation of tribal belief systems [46].

There is some evidence that specific ethnic minority groups are less familiar with or have more misconceptions about advance directives compared with whites. For example, in a study of 112 Korean American and 105 white elders, only 5% of the Korean Americans had advance directives compared with 59% of their white counterparts [82]. In this study, it was not necessarily lack of knowledge that contributed to the disparity. Rather, Korean culture's adherence to family involvement in decision making was identified as a major barrier.

In a study with three groups of Japanese individuals (i.e., English-speaking Japanese Americans, Japanese-speaking Japanese Americans, and Japanese living in Japan), there were no significant differences among the groups in terms of having discussed advance directives with their physicians [83]. In addition, they all preferred a group decision-making model, conforming to Asian values emphasizing the collective. In a study with elderly Chinese patients, participants were resistant to the idea of advanced directives. They did not see a necessity for formal advanced directives as family are expected to intercede [180].

In one study, Hispanics were less likely to complete advance directives compared with white Americans [130]. For some, religious beliefs can be a barrier to setting up advance directives. If one believes that God has ultimate control, actively planning one's death will feel incongruent [150]. In qualitative interviews with ethnic minorities, Hispanic participants indicated that they did not want to sign advance directive forms for fear of deportation [131]. O'Mara and Zborovskaya assert that healthcare providers are in a unique position to help educate Hispanic/Latino patients about advance directives by taking advantage of the cultural value of *jerarquismo*, which emphasizes respect for hierarchy [142].

Compared with White Americans, African Americans are also less likely to plan for end of life and use advance directives [84; 132]. In one study, white participants were more likely to identify benefits of end-of-life planning, while African Americans were more likely to identify barriers [132]. Although advance directives, living wills, and power of attorney directives are less common, African Americans tend to choose more aggressive lifesaving interventions than whites [85]. While they are less likely to rely on formal written advanced directive documents, they are more likely to discuss end-of-life issues and planning with family members. Consequently, end-of-life planning for African Americans are more family-oriented, informal, and collectivistic [181].

Some speculate that African Americans' experiences with institutional oppression, racism, and discrimination play a role in these trends. Examples of medical abuses (e.g., the Tuskegee experiment) may make African Americans more likely to aggressively protect themselves, which manifests as taking steps to prolong life. Experiences of oppression, which are rooted in slavery and the Jim Crow laws, may result in African Americans being fearful of giving up control, particularly to those representing the dominant culture [86]. As with the sociopolitical backdrop of oppression in African American culture, some immigrant and refugee groups who have been politically persecuted and exploited in their home countries may be wary of signing legal documents [87]. Among these groups, advance directives are often viewed with skepticism.

Another factor in the non-adoption of advance directives is the role of religiosity and spirituality. Some have suggested that the disparity of advance directive use between whites and African Americans may be related to differences in beliefs regarding God's role in controlling life and death. Furthermore, cultural values about individualism/collectivism and future/present orientation appear to influence older individuals. In one study, older White individuals spoke more often about individualism/self-reliance and tended to have a future orientation while their older African American counterparts, who focused on collectivism/interconnectedness and tended to have a present orientation [132].

PALLIATIVE CARE

Palliative care is the noncurative care provided to patients to relieve symptoms and improve quality of life [88]. The goal of palliative care is to not only meet patients' physical needs but also address their psychologic, social, religious/spiritual, and cultural needs [89]. Even across cultures, there appear to be common denominators for effective palliative care. In an analysis of studies on palliative care in various ethnic/racial minority groups, researchers found common cultural themes that cut across all groups in the area of palliative care [90]. These included:

- Pain management
- Support to achieve closure (i.e., resolve social and emotional concerns that are hindering well-being)
- Spiritual and religious care
- Support to family and friends
- Focus on the quality of life

The priorities set by patients and healthcare professionals were considered carefully in the structuring of clinical practice guidelines for high-quality palliative care developed by the National Consensus Project for Quality Palliative Care. These guidelines are organized according to eight domains [91]:

- Structure and process of care
- Physical aspects
- Psychologic and psychiatric aspects
- Social aspects
- Spiritual, religious, and existential aspects
- Cultural aspects
- Care of the imminently dying patient
- Ethical and legal aspects

In its proposed national framework for palliative and hospice care, the National Quality Forum set forth 38 preferred practices based on these eight domains [91]. Of these preferred practices, six refer directly to the spiritual and cultural care of the dying patient (***Table 2***).

At the end of life, palliative care is delivered most effectively through hospice, and the use of hospice care has been increasing in the United States [92]. Despite these trends, hospice/palliative care remains underused, particularly among racial and ethnic minorities. For example, fewer than 9% of hospice care recipients are African Americans [93].

The National Hospice and Palliative Care Organization, which provides data on patterns of hospice and palliative care service use in the United States, estimates that 1.55 million Medicare patients received services from hospice in 2018 [94]. The majority (82%) were white, 8.2% were African American, 6.7% were Hispanic, 1.8% were Asian, and 0.4% were Native American. These disparities exist for many reasons, including significant differences in values among cultural groups. As with much of Westernized health care, the values underlying palliative care are based on the ethical notions of autonomy, informed consent, and capacity, which may be culturally dissonant to many groups [88].

Many African Americans perceive the use of hospice care as giving up, and given their experiences with adversity, this is considered weak and unacceptable [93; 126]. In focus groups, African American participants disclosed that hospice meant "imminent death," "giving up," and a place for family members to "come and watch you die" [126].

African Americans also tend to have extensive social networks, including family, church, and the community, that they historically rely on in times of crisis [95]. Similarly, Asian Americans and immigrants have strong cultural values regarding the role of the family at the end of life. As a result of this cultural emphasis, many view hospice as a form of abandonment of the sick and dying. Hospice is often considered a sign that family members are unable to fulfill their responsibilities of filial piety, which is shameful [96]. Like other Asian groups, Asian Indians tend to prefer for terminally ill family to die at home in order to ensure a good death. The Hindu culture has many end-of-life rituals that are performed by family members; dying at home is more conducive to this

PREFERRED PRACTICES FOR PALLIATIVE AND HOSPICE CARE RELATED TO SPIRITUAL AND CULTURAL DOMAINS

- Develop and document a plan based on an assessment of religious, spiritual, and existential concerns using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
- Provide information about the availability of spiritual care services, and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
- Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.
- Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.
- Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
- Provide professional interpreter services and culturally sensitive materials in the patient's and family's preferred language.

Source: [91] *Table 2*

process [70]. However, because much of hospice care is now delivered to patients at home, it may become a more desirable option to these groups in the future.

In a focus group study of Mexican Americans, participants indicated providing medical care for the terminally ill was the responsibility of the family and that the family should assist the patient to die with dignity [97]. Many participants also stressed the importance of having priests available at the end of life, as Catholicism is a significant aspect of most traditional Mexican and Latino families.

In many Asian families, the responsibility of care is believed to be the responsibility of the family. Providers can respect this belief by assuming the role of educator. For example, a nurse can instruct family members how to safely change the patient's positioning [135].

CULTURALLY SENSITIVE COMMUNICATION STRATEGIES

Most health communications can be classified as patient-centered or family-centered. Patient-centered communications consist of practitioners discussing decisions with the patient first, emphasizing autonomy and individuality. On the other hand, family-centered communication relies on group discussions involving the patient and his or her (self-defined) family. This type of communication is based on collectivistic cultural values and entails conducting a thorough assessment of the family's cultural, religious, and spiritual preferences and documenting that all members of the team have access to this information [37; 182].

If health communication is viewed on a continuum with patient-centered and family-centered as two end-points, practitioners can assess the patient's and the family members' stance by asking two questions [37]:

- Do you want us to tell you (the patient) everything about your illness or do you want us to tell your family? Both? Neither?
- Do you (the patient) want to make decisions about your treatment or do you want others to make decisions?

Some experts recommend using the "ask-tell-ask" communication strategy to ensure a two-way conversation between the patient, family members, and providers [141]. This approach involves the provider encouraging the patient and family to provide their perspectives of the illness and health care. The provider may then offer assistance and/or information. Finally, the provider should ask the patient/family what information they can practically apply and what other concerns they have. Such conversations cannot be rushed, as family stories are complex and establishing rapport takes time [151]. Asking open-ended questions and reflexive listening are crucial [182].

ASSESSMENTS

Communicating effectively about palliative care and assessing patients' needs requires both cultural sensitivity and skills specific to the end-of-life setting [80]. The following questions may be helpful when assessing patients' and families' cultural, linguistic, and spiritual needs at the end of life:

- What language does the family speak when discussing health issues?
- How open are they in talking about diagnoses, prognosis, and death? With whom will they be open to talking about these issues?
- Who appears to be the decision maker (e.g., the patient or another family member)? How do gender roles influence decision making?
- What are the patient's and family's views about death and the role of each person in the family and healthcare team in relation to death?
- What is the patient's and family members' level of fatalism regarding the illness and prognosis?
- How do religiosity and spirituality influence views about death?
- Are additional sources of culturally sensitive information (e.g., interpreters, community workers, persons with expertise regarding a specific culture) necessary?
- What role does hope play for the patient and family?

EVIDENCE-BASED PRACTICE RECOMMENDATION

According to the Institute for Clinical Systems Improvement, the cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences. Cultural decisions affecting palliative care also include attention to gender, age, generation, education level, diet/food and ritual. Clinicians should ask the patient/family about these considerations,and keep in mind that every patient conversation is a cultural conversation.

(https://www.icsi.org/wp-content/uploads/2020/01/PalliativeCare_6th-Ed_2020_v2.pdf. Last accessed August 26, 2021.)

Strength of Recommendation/Level of Evidence: Guideline (Expert opinion)

In 2011, the Joint Commission implemented assessment standards for healthcare providers working with patients from culturally diverse backgrounds in hospitals. The following questions are specific for healthcare professionals caring for patients at the end of life [114]:

- Which cultural background does the patient identify with?
- Are there cultural beliefs or traditions that the patient adheres to?
- What is the role of the family in the patient's care?
- Does the patient want family involved in the treatment plan?
- Who makes the decisions about advance directives and treatment options at the end of life? Is it the family, patient, or someone else?
- Does the patient have any religious or spiritual beliefs?
- What is the role of religion in making decisions about illness and treatment?
- Would the patient prefer a visit from a religious leader or clergy member?
- Who can be present for the death?
- What does the patient believe about the body after death? In addition, how is the body to be treated?

- How does the patient want to manage comfort and pain?
- How does the patient want to say goodbye?
- Does the patient want to die at home or in the hospital?
- Who will make final plans?
- How can the healthcare professional honor the patient's spiritual beliefs as death approaches?
- Who will communicate between the patient and healthcare professional?

It is important for practitioners to be open and curious about diversity and cultural issues and to consider patients and families to be experts of their own culture [90]. Practitioners can then take this information and attempt to apply it within the context of dying and palliative care. According to Bosma et al., "deliberately assuming a clinical position of 'not-knowing' establishes a non-threatening tone for engagement with culturally diverse patients and families, which can evoke descriptions of their individual understanding, needs and goals at end of life" [90]. This "not-knowing" position is in stark contrast to the biomedical model, which positions the practitioner as the expert.

Practitioners should not make assumptions about the preferences of the patient or family on the basis of cultural beliefs. Even within a single culture or ethnicity, the level of information desired, preferences for treatment, role of other family members in decision making, and goals of care differ among patients and families [98; 99]. Assessment is continuous and requires careful observation [140].

THE ROLE OF INTERPRETERS

In clinical situations in which there are language barriers between practitioners and the patient and/or family members, miscommunication, dissatisfaction with care, and premature termination of services can occur. When terminal illnesses and end-of-life issues are part of the discussion, communication can be even more difficult. In these cases, interpreters may be needed. It is important to differentiate between informal/ad-hoc versus trained interpreters. Ad-hoc interpreters are often used by health professionals because it may be difficult to access an interpreter who can speak a specific language and/or dialect. Time pressures may also result in providers turning to any family or friends present for interpretation [169].

EVIDENCE-BASED PRACTICE RECOMMENDATION

The Institute for Clinical Systems Improvement recommends that clinicians should also follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English.

(https://www.icsi.org/wp-content/uploads/2020/01/PalliativeCare_6th-Ed_2020_v2.pdf. Last accessed August 26, 2021.)

Strength of Recommendation/Level of Evidence: Guideline (Expert opinion)

Many view interpreters merely as neutral individuals who communicate information back and forth. This approach to interpretation, common in healthcare settings, is referred to as the "interpreter as a conduit" model. Practitioners adopting this perspective view interpreters as tools to relay information back and forth, discounting their human nature, emotions, and independent knowledge [100].

Another approach is to view interpreters as active agents, negotiating between two cultures and assisting in promoting culturally competent communication and practice [101]. This role is closer to that of a co-diagnostician, as interpreters decide which medical information is valuable, seek illness-related information independently, and participate in the diagnostic process by identifying signs or symptoms [102].

Medical interpreters also often perform cultural brokering, providing cultural information to health providers and gauging if information is conveyed too directly. Using culturally appropriate words in the target language helps to contextualize the medical terminology [183].

In a study conducted with 43 medical interpreters, the participants confirmed that they were active agents in the clinical encounter [103]. In addition, the interpreters identified specific qualities that improve end-of-life communications between practitioners and patients/families who speak different languages. These qualities include [103]:

- Balancing between interpreting word-for-word versus being an advocate, cultural broker, and/or educator
- Acknowledging that language and culture are different (i.e., the interpreter and the patient/family members may speak the same language but may not share the same culture)
- Allowing enough time with family members and the patient
- Addressing any religious or spiritual issues that arise in the clinical encounter
- Being aware of personal discomforts that may arise given the sensitive and stressful nature of the encounter

Word-for-word interpretation can lead to confusion or anxiety in certain contexts. For example, if the word "hospice" is translated to *hospicio* in Spanish, it could be understood as an orphanage or an asylum [135].

They also recommended that practitioners meet with interpreters prior to and after the delivery of bad news to family members and patients. The meeting prior to the delivery of bad news will allow interpreters to provide culturally specific information to practitioners, if appropriate. In addition, it should be established whether practitioners expect interpreters to merely interpret or to help with cultural brokering. After the delivery of bad news, it is equally vital to have the opportunity to debrief [103].

When considering the use of interpreters, it is often conceptualized as a binary choice—to use or not use [133]. However, it may be more useful to conceptualize interpreter participation along a continuum [133]. If a patient does not speak English, then it is vital to call upon the services of an interpreter. However, an over-reliance on an interpreter can inadvertently minimize client's or patient's sense of self-efficacy. When a patient has the ability to switch back and forth between English and his or her native language, an interpreter can assist in elaborating on thoughts [133].

INTERPROFESSIONAL COLLABORATION

Interprofessional collaboration is defined as a partnership or network of providers who work in a concerted and coordinated effort for the common goal of improving patients' health, mental health, and social and/or family outcomes [184]. Positive outcomes have been demonstrated on the individual and organizational levels with interprofessional collaboration [185; 186; 187]. However, implementing and promoting this approach can be challenging. Not understanding each other's roles is another barrier.

CULTURALLY SENSITIVE PRACTICE AT THE END OF LIFE: ETHICAL CONSIDERATIONS

Health care in the United States is based primarily on the Western ethical principles of respect for persons and beneficence [18]. The underlying premise of respect for persons is autonomy, or the belief that patients should be able to make their own decisions about their health care. In order for patients to make an informed decision, truth telling and full disclosure are necessary. In terms of death and dying, patients are given all of the information available regarding their terminal condition and prognosis (even estimates of time left to live) because it is believed to be moral and ethical [104]. However, as discussed, truth telling as it is practiced in Western medicine is not universally accepted in all cultural groups. Some argue that autonomy is not necessarily a dichotomous principle; rather, it can be demonstrated on a continuum [188]. Relational autonomy is more suited to working with racial and ethnic minorities in end-of-life care. This concept entails taking into account the cultural, social, and familial contexts of patients and their decision-making and incorporates compassion, hope, empathy, and responsibility [188]. To address this possible gap, practitioners can review informed consent with patients, following the principles of respect for persons and autonomy, and follow up by inquiring whether the patient would like other family members to be involved in decision making. This allows the patient to act as an autonomous agent in a culturally sensitive way [30].

Consent forms are also an essential part of health care and the legal system in the United States. A signed informed consent form indicates that appropriate information was given or communicated and the patient acknowledges having received and comprehended the information and/or agrees with a prescribed course of action [105]. However, in many cultures, consent is not considered to occur until the family has been informed [18]. Informed consent is a process and should not be viewed as a one-time event. Rather, informed consent should be viewed as a continuous process of evaluating what the patient and family want to know and the extent to which they comprehend the information [105].

As discussed, the notion of "self" is at the heart of Western ideologies of individualism. The challenge comes when working with patients and family members from racial and ethnic minority groups whose cultural value systems focus on collectivism rather than individualism. Focusing on Western principles of autonomy can lead to isolating and disempowering the patient [134].

Assessments can be conducted to determine patients' decision-making patterns (i.e., patient-centered vs. family-centered). This information can then be communicated with practitioners who are responsible for obtaining informed consent [106].

The ethical principle of beneficence, or the duty to do good, is also the foundational basis of most healthcare professionals' codes of ethics. Johnstone and Kanitsaki observe the following [107]:

Providers are also often bewildered and frustrated by what they see as a negative attitude and at times hostile resistance toward advance care planning by patients and involved families of diverse cultural backgrounds and their apparent inability to understand and accept the intended benefits (and benevolence) of advance care planning and related respecting patient choices programs. Patients and involved families, meanwhile, are often left bewildered and frustrated by the inability of providers to understand and accept the benevolence and justice of their actions, which have as their sole objective protecting the life and well-being of their loved ones—whatever the medical prognosis.

Family members should not be viewed as intrusive but as an integral part of the clinical process [107]. As important members of the healthcare team, their beliefs regarding the best course of action for the patient are to be respected. They may be involved in the decision-making process, if the patient wishes for this to be the case [107].

The ethical principle of distributive justice (i.e., ensuring equal access to health and end-of-life services) can be promoted by healthcare providers by being sensitive and discerning when mitigating the barriers immigrants and refugees often experience [134]. For example, when using interpreters, it is crucial to determine if interpreters are developing multiple roles. For example, if the interpreter is also an immigrant or refugee living in the same ethnic community as the patient, this can cause discomfort for both parties [9]. The fear that the interpreter will disclose sensitive information to others in the community can impede patients from continuing with services [9].

CONCLUSION

According to Nkongho, "human growth and development take place within all cultural groups, and the cultural group's influence on personality is continuous through life" [108]. Given the ever-changing demographics of the United States and the growing role of multiculturalism, it is certain practitioners will encounter cultural diversity in their patients and their family members. Healthcare disciplines are calling for more holistic care that encompasses physical, psychologic, social, spiritual/religious, and emotional components. As such, it is essential to take into account the cultural background of patients and families when conducting assessments and creating care plans at the end of life [109].

FACULTY BIOGRAPHY

Alice Yick Flanagan, PhD, MSW, received her Master's in Social Work from Columbia University, School of Social Work. She has clinical experience in mental health in correctional settings, psychiatric hospitals, and community health centers. In 1997, she received her PhD from UCLA, School of Public Policy and Social Research. Dr. Yick Flanagan completed a year-long post-doctoral fellowship at Hunter College, School of Social Work in 1999. In that year she taught the course Research Methods and Violence Against Women to Masters degree students, as well as conducting qualitative research studies on death and dying in Chinese American families.

Previously acting as a faculty member at Capella University and Northcentral University, Dr. Yick Flanagan is currently a contributing faculty member at Walden University, School of Social Work, and a dissertation chair at Grand Canyon University, College of Doctoral Studies, working with Industrial Organizational Psychology doctoral students. She also serves as a consultant/subject matter expert for the New York City Board of Education and publishing companies for online curriculum development, developing practice MCAT questions in the area of psychology and sociology. Her research focus is on the area of culture and mental health in ethnic minority communities.

Implicit Bias in Health Care

The role of implicit biases on healthcare outcomes has become a concern, as there is some evidence that implicit biases contribute to health disparities, professionals' attitudes toward and interactions with patients, quality of care, diagnoses, and treatment decisions. This may produce differences in help-seeking, diagnoses, and ultimately treatments and interventions. Implicit biases may also unwittingly produce professional behaviors, attitudes, and interactions that reduce patients' trust and comfort with their provider, leading to earlier termination of visits and/or reduced adherence and follow-up. Disadvantaged groups are marginalized in the healthcare system and vulnerable on multiple levels; health professionals' implicit biases can further exacerbate these existing disadvantages.

Interventions or strategies designed to reduce implicit bias may be categorized as change-based or control-based. Change-based interventions focus on reducing or changing cognitive associations underlying implicit biases. These interventions might include challenging stereotypes. Conversely, control-based interventions involve reducing the effects of the implicit bias on the individual's behaviors. These strategies include increasing awareness of biased thoughts and responses. The two types of interventions are not mutually exclusive and may be used synergistically.

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