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## Providing Culturally Respectful Care for Seriously Ill Vietnamese Americans

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### Abstract

Vietnamese Americans are a heterogeneous population with a rich, shared experience and historical and cultural influences from Asia and Europe. Societal upheaval resulting from the Vietnam War and varied immigration patterns to the U.S. and levels of acculturation layer complexity to this resilient population. These experiences influence how the communities as a whole and how the family as a unit approach health care issues, their attitudes toward serious illness and care at the end of life. Challenges with caring for this population include lack of resources and training to provide culturally sensitive care, lack of appropriate advance care planning, and lack of interpreters or culture-specific care programs. All contribute to poor end-of-life care. An understanding of how these complexities interplay may help clinicians provide compassionate and patient-centric care to these patients, their families, and their supporting communities. This article provides an overview of culturally effective care for seriously ill Vietnamese American patients and makes recommendations for potential strategies for providing respectful end-of-life care

### Introduction

#### Overview of Vietnamese Immigration to the U.S.

Before 1975, there were few Vietnamese immigrants in the U.S., with most being academic personnel and their family, spouses or children of the American military, and some arriving to perform various menial jobs. The first large-scale immigration to the U.S. began after the

fall of Saigon in 1975, which ended the Vietnam War. The U.S. evacuated an estimated 125,000 refugees during this first wave. These early refugees tended to be highly educated urban professionals with strong ties to the U.S. and intimate knowledge of Western culture. Most were proficient in the English language with more than 30% of the heads of household being medical professionals or technical managers.<sup>1</sup> These refugees arrived at American military camps in the Philippines and Guam before being transferred to military bases in California, Arkansas, Florida, and Pennsylvania.

Later groups of refugees arrived during the late 1970s to mid-1980s and were more diverse, with a mix of highly educated professionals and those less educated and less familiar with Western culture, urban dwellers and those from rural backgrounds, and ethnic minorities in Vietnam. Most were escaping political and economic instability under the new communist government. The plight of these refugees led to the U.S. Refugee Act of 1980, which admitted to the U.S. 280,500 Vietnamese refugees from 1978 to 1982.<sup>2</sup> From 1981 to 2000, the U.S. accepted another 531,000 Vietnamese refugees based on their status of being employees of the U.S. government or American companies during the war, children of U.S. servicemen and their family, and through immediate relatives to U.S. citizens. Although initially scattered throughout the U.S., eventually, many refugees congregated in states with large Vietnamese populations, namely California and Texas. In 2017, the U.S. Census Bureau estimated the total population of Vietnamese Americans at 2,104,217, 36% of whom were residing in California and 14% were residing in Texas.<sup>3</sup> Despite the trend toward migrating to states with higher Vietnamese populations, individual families have experienced strained or severed familial bonds because of war, poverty, and political strife. There are also generational differences in how these changes in family structure are processed and integrated into their lives, which are magnified when a family member becomes seriously ill.

### **Patterns of Health Risk: Causes of Morbidity and Mortality**

Knowledge about morbidity and mortality of Asian Americans is based primarily on aggregated data, with sparse and patchy data about individual Asian subgroups, which often vary by immigration patterns, disease occurrence, and socioeconomic backgrounds. Despite the knowledge gap, some data do exist specifically for Vietnamese Americans. Between 2003 and 2011, the age-adjusted mortality rate (average death rate over 2003–2011 divided by estimated 2007 population and adjusted for age) for Vietnamese American women was 330.7 and for men was 441.2.<sup>4</sup> The top three causes of death for Vietnamese Americans were malignancies (27.9% for women, 32.5% for men), cardiovascular disease (19.1% for women, 17.8% for men), and cerebrovascular disease (10.7% for women, 7.8% for men).<sup>4</sup> Age-adjusted cancer mortality rates per 100,000 in Vietnamese American women were 23.3 for lung cancer, 10.4 for liver cancer, and 9.0 for breast cancer, although Vietnamese women die from cervical cancer at the highest rate among Asian American women.<sup>5</sup> The incidence of cervical cancer (7.3/100,000) was nearly twice that of Non-Hispanic whites, whereas the prevalence of Papanicolaou testing was significantly less for Vietnamese women (69.8%) than for Non-Hispanic whites (83.8%).<sup>5</sup> Age-adjusted cancer mortality rates per 100,000 in Vietnamese American men were 47.2 for lung cancer, 35.5 for liver cancer, and 15.5 for stomach cancer, although Vietnamese men die from liver cancer at the highest rate among

Asian American men.<sup>5</sup> There is a 14% rate of hepatitis B virus infection, the most common cause of hepatocellular carcinoma worldwide, whereas Vietnamese men have one of the highest smoking rates among all ethnic subgroups.<sup>5</sup>

As war refugees, many Vietnamese witnessed violence and experienced profound loss before their arrival in the U.S. Both psychological and physical trauma can result in specific behaviors that contain elements of post-traumatic stress disorder (PTSD) and symptoms of intense grief or even depression,<sup>6</sup> which has approximately 30% prevalence in the Vietnamese population. Risk factors for depressive symptoms and psychological distress include female gender and safety of the place of residence as well as issues surrounding loss, including economic loss (such as with employment and income), familial losses, losses in physical health, and losses associated with cultural identity, which are all risk factors for intentional self-harm (suicides).<sup>7, 8</sup> In fact, suicide is the sixth cause of death among Vietnamese American men (2.9%) and is at a higher rate than non-Hispanic whites.<sup>4</sup>

Refugees often experience a longing or yearning for their traditional customs, home country, and extended family. The distress may be increased in those who lost loved ones in Vietnam as some of the cultural and religious rituals that act as transitional steps in accepting the loss may not have been possible.<sup>6</sup> The loss of one's homeland can be described as "cultural bereavement" and is a reaction to the loss of self-identity, social structures, and cultural values. These losses can result in significant existential pain at the end of life as they come to terms with an inability to recapture the lost past and worry about the survival of their culture.<sup>9</sup>

Furthermore, experiencing a significant life stressor such as death of a spouse or the loss of health or independence can precipitate symptoms consistent with PTSD decades after the initial inciting trauma. For older individuals, these symptoms can at times be mistaken for depression or a medical issue rather than PTSD. For families caring for a dying loved one, the loss of access to culturally appropriate foods and permission for salient religious ceremonies can be significant stressors. It is important to note that the Western diagnostic criteria of psychiatric disease assess human behavior within the context of Western medicine. This approach may not be suitable for patients from ethnic minorities or immigrants. Specifically, it is important to note that healing from emotional trauma occurs in many ways, and that the majority of healing occurs in the setting of family, community, spirituality, and political changes rather than medicine per se.<sup>10</sup>

### **Social Structure**

Vietnamese culture emphasizes family welfare and parental status over individual welfare. Recognition of one's "debt" to previous generations serves to reinforce and solidify one's place within the extended family. Some traditional families burn incense and votive paper to honor their ancestors and believe that the departed spirits will reciprocate by providing comfort and protection to living relatives. This theme of reciprocity extends to food items left at the altar for their ancestors to consume. Those in the spirit world are fortified by the essence of the material food, and those who eat the food from which their ancestors have found sustenance receive *n lộc*—beneficence that relates to good luck, fortune, prosperity, and divine benevolence.<sup>11</sup>

Thus, the deep connection to earlier generations who sacrificed during the war may result in a heightened sense of indebtedness at the end of life. There is deep respect paid to elders and ancestors, where extended households either within the same residence or in nearby residences are common. Nearly 15% of households have some other relative (besides householder, spouse, and children) living within the same residence.<sup>12</sup> Much of this tradition comes from centuries of influence from China, which brought Confucianism and Buddhism.

Education and learning are highly respected and viewed by many in the older generation as an avenue to a more prosperous life. Many Vietnamese Americans have worked their way up from menial labor to have their second-generation children attend universities and become successful. With that success, however, the younger generation has become acculturated to Western values, which often challenges traditional Vietnamese values. Vietnamese American parents of these children typically have decreasing levels of authority. As a result, nuclear families are becoming much more common, and individualism, rather than filial piety, is more highly valued. Despite that, decision-making in most matters typically rests with the family's oldest male.<sup>13</sup> In particular, within Vietnamese culture, social harmony is essential and thus maintaining one's place within the social structure is valued. Conflict within the family and with others is often avoided, with older generations avoiding openly disagreeing and younger generations often being more comfortable expressing opinions. Furthermore, those from Western culture may not appreciate that strong emotions can be discouraged within Vietnamese culture so patients may work to maintain a flattened affect or attempt to smile<sup>14</sup> even when they may be experiencing profound suffering. Health professionals are at risk of underestimating pain and distress in these patients. Also, rules and regulations of health care institutions (e.g., visiting hours, number of visitors at a given time, gifts of food) may further isolate the patients and amplify their suffering at their time of greatest need.<sup>15</sup>

### **Philosophy: Confucianism and Karma**

Confucianism has influenced Vietnamese traditional values in four core domains including an obligation to the family, desire for reputation, fondness for learning, and respect.<sup>16</sup> The family centers most of social life with filial piety and duty often seen as compulsory. Children are "indebted" at birth and are expected to care for parents when they are old. This is often displayed as respect for elderly people. Reputation is seen as important not only in life but also in death and can be acquired by heroic achievements, intellectual advancements, and by display of moral virtues.<sup>17</sup> Obtaining a high level of education is seen as a way to climb the social ladder and achieve prosperous work opportunities, which will often garner community respect. This respect may play out in Western health care systems as deference to physicians though such behaviors may cause internal conflict with the patient's religious and traditional beliefs.

Karma is also an essential concept for Vietnamese Buddhists. Death is often seen as a relinquishing of the body (a temporary vessel), and the soul is eternal and is reborn. How that rebirth occurs is dependent on previous actions. Sinful actions may result in undesirable rebirths, like to animals, whereas terrible and painful deaths may be the result of bad behavior in the current or prior life. In addition, a child may die because of misdeeds in a

past life or misdeeds of a close family member. To achieve a higher level of rebirth and have a good next life, the goal is to live without karmic debts.<sup>18</sup>

### Religion: Buddhism and Catholicism

Buddhism is divided into two major schools: Hinayana (or Theravada) and Mahayana. In Vietnam, most Buddhists follow the Mahayana tradition, although in practice there is not as clear a demarcation between Hinayana and Mahayana teaching as there is between Christian branches (e.g., Catholicism and Protestantism). The result of this lack of distinction is that there is no “one” form of Buddhism that is practiced by all Vietnamese patients, and thus, respectful discussion of their spiritual needs, especially near the end of life, becomes essential.

Furthermore, the needs of the dying patient can vary significantly depending on the level of spiritual practice that an individual has attained.<sup>19</sup> In Buddhism, the process of dying is an integral part of the preparation for the next life. In particular, maintaining mental clarity as one approaches death to allow the patient to meditate and contemplate is essential.

Without an awareness of this spiritual goal, misunderstandings around the use of analgesics, such as opioids, and the benefits of palliative sedation can occur.

Similarly, the hospital environment itself can be disruptive to the patient’s efforts to meditate, and thus, efforts should be made to limit interruptions and noise. Vietnamese Buddhist monks and nuns who have taken a vow of celibacy may feel more comfortable being cared for by nurses of the same gender.<sup>19</sup> In some circumstances, their spiritual leader may try to remove distractions from the dying person to facilitate their spiritual acceptance of their death. Occasionally, this effort may result in loved ones and those unable to hide their emotions being separated from the patient as they die.<sup>20</sup>

Vietnamese Americans who practice Catholicism have many similarities to other ethnic Catholic communities and are bound together by a common religiocultural heritage and socioeconomic context.<sup>21</sup> Generally, the Roman Catholic Church standardizes liturgical rites worldwide, although differences in ethnic and local customs may be acknowledged and practiced as long as they do not alter a Roman ritual or demonstrate a belief that is different from official Church dogma. For the Vietnamese, because family plays a crucial role in both social life and the practice of Catholicism, Vietnamese often emphasize the familial and relational aspects of rituals, including those related to death and funerals. The colors and types of garments worn, mourning periods, and processions and locations of burial all indicate the type and strength of the relationships that exist between the deceased and the living.

### Health Practices

**Health Care Access**—Similar to other racial and ethnic minority Asian groups, Vietnamese immigrants can be identified based on phenotypic traits and hence may experience subliminal and overt bias and racism from the health care team.<sup>15</sup> They may face social inequalities that include discrimination in the health care system, language barriers, and limited access to health care, which leads to higher rates of morbidity and mortality.<sup>22</sup>

Vietnamese Americans tend to have the lowest income and education levels compared with other Asian American ethnic subgroups and have the second lowest prevalence of health insurance among Asian ethnic groups, thus creating barriers to obtaining adequate preventative health services.<sup>5</sup> Foreign-born Vietnamese are a particularly disadvantaged group with 14% in poverty (16.6% for Vietnamese immigrants age 65 years or above) and 30% of adults with less than a high school education.<sup>22</sup>

This leads to higher rates of many chronic illnesses including cancer, cardiovascular and cerebrovascular diseases, hypertension, diabetes, hyperlipidemia, and depression.<sup>23</sup>

**Traditional Health Beliefs**—Many Vietnamese Americans view health and disease from multiple perspectives including more traditional spiritual and mind-body teachings to more Western frameworks of disease causation. This broad perspective often drives Vietnamese patients to combine elements from different perspectives to try to achieve the best health outcomes. Vietnamese may consider supernatural or spiritual forces in contributing to illness and may call on religious specialists to help with chanting, magical potions, and recitation from ancient texts or spiritual protection in the form of talismans, such as amulets or other spiritual objects. This may be combined with the concept of internal balance between the alternating vital forces of âm and dương (translated to “cold and hot,” similar to the Chinese concept of Yin and Yang, although this does not necessarily refer to temperature or spiciness).<sup>24</sup> Imbalance results in disease, and restoring balance may involve dietary changes, cupping, coining, pinching, minor bloodletting, steaming, balm, acupuncture, acupressure, or herbs.<sup>24</sup>

The Western concept of disease causation is generally accepted among most Vietnamese patients, particularly that disease can come from environmental contaminants or infectious agents. There is an expectation for the Western health system to immediately provide symptom relief and cure, and when a medication is not prescribed, the patient may seek care elsewhere. In addition, Vietnamese patients often discontinue medications after symptoms disappear, and if symptoms are not manifest, they may not perceive that illness is present. Some Vietnamese patients resist invasive procedures that may result in blood loss, including laboratory draws and surgery. It is believed by some that the loss of blood will make them sicker and the removal of any organs would alter the internal balance. Food is particularly important in maintaining balance and health and may expect their health care providers to integrate nutrition with other treatment recommendations.

With regard to mental health diagnoses, traditional beliefs concerning the etiology may relate to malevolent spiritual beings, curses, imbalances between the body and spirit, and lack of religiosity or blessings from religious leaders. Mental disorders may be blamed on demonic possession or punishment for prior sins. Similar to other disorders, an unhealthy diet is a popular explanation for mental illness. These beliefs are significantly associated with levels of acculturation and may result in barriers to receiving health care.<sup>25</sup>

**Attitudes Toward Serious Illness: Truth-Telling, Decision-Making Approach, and Discussing End-of-Life Issues**—Discussions around diagnosis and prognosis will vary depending on the degree of acculturation. There is a generational gap causing a cultural



shift within the Vietnamese population, leading to differences in how health care decision-making is approached. Older Vietnamese immigrants who have not acculturated to Western values tend to practice a more traditional collectivistic approach and view life and life decisions in this collective manner.<sup>26</sup> Collectivism gives priority to familial goals and shapes behavior and decisions around communal norms.<sup>27</sup> Any decision made is based on how it may affect their family and relationships. Individuality and autonomy are not included in the decision-making process, even with regard to a particular patient's own health. The family members, particularly older males, are included in every important decision. In contrast, Vietnamese Americans who have acculturated to Western values tend to take a more individualistic approach, where individuals make independent and autonomous decisions on behalf of their well-being.<sup>26</sup> Younger Vietnamese Americans adhering to this approach are no longer conforming to traditional cultural values, which may lead to family conflict. Owing to this generational cultural shift, older Vietnamese may feel isolated or confused and are at risk for having the highest unmet health needs.

In the U.S., patient's self-determination and the subsequent process of informed consent around treatment choices and knowledge of the diagnosis and prognosis were elevated with the passage of the 1973 Patient Bill of Rights. This shared decision-making process that values autonomy tends to be concordant with those that are acculturated with Western ethical ideals and practice individualism but may cause challenges with those who are not fully acculturated and practice a collectivistic approach. This is particularly important around the concept of truth-telling. Assuming a Vietnamese patient would not want to be told a diagnosis or prognosis because the patient is Vietnamese is stereotyping, whereas insisting on truth-telling and violating the right not to be told are forms of "cultural imperialism" (26–28). Clinician insistence in truth-telling to those patients who decline to discuss end-of-life issues may be perceived by the family as cruel or uncaring and may result in mistrust.<sup>28</sup> The goal is to attempt to navigate these values in a culturally appropriate manner. It must be recognized that a patient who does not want to participate in truth-telling is also exercising a form of autonomy. The particular issue with truth-telling is not that there is a dichotomous choice on whether to tell patients the truth or not. Rather, it is how best to approach truth-telling within the context of the patient's and the family's specific needs and abilities to process difficult information. Even patients who may not want direct disclosure may wish to know through other means, such as indirectly, euphemistically, or nonverbally.

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### Advance Care Planning

It has long been known that advance directives, which value autonomous, individualistic decision-making, appeal to educated, insured, middle-class white people, rather than various racial or ethnic minorities.<sup>26, 29</sup> Advance directives currently used throughout the U.S. can often be biased or ineffective for these culturally diverse groups.<sup>26</sup> For many older Vietnamese adults, active end-of-life planning was an unfamiliar task with many unaware of their options regarding cardiopulmonary resuscitation and other life-sustaining treatments, including feeding tubes.<sup>18, 26</sup> Discussing death and dying may be viewed as inauspicious and in poor taste with a perception that consenting to end-of-life support may actually contribute to death.<sup>23</sup> However, it is common practice that many older Vietnamese adults

take on the responsibility to make preparations for death including burial arrangements and choosing a burial site.<sup>23</sup> Death preparations may also include praying and preparing wills for distribution of property.<sup>18</sup> Approaching advance directives should be done with sensitivity, and clinicians should be attuned to variations in cultural practices.

### Attitudes Toward Palliative Care and Hospice

When a Vietnamese person is diagnosed with a terminal illness, a multitude of cultural factors come into play. The importance of including the family in discussions and decision-making cannot be understated. Families may often request the physician refrain from discussing a terminal prognosis with the patient, as it is commonly believed that talking about such things may bring bad luck, engage sinister spirits, or lead to the topic at hand coming to fruition.<sup>30</sup> Many families believe that talking to a patient about their terminal diagnosis may cause them to lose hope.<sup>30</sup>

Nevertheless, many families understand the inevitability of these conversations and will expect to be a part of them. When having such discussions, being mindful of the traditional familial hierarchy in Vietnamese families is essential. The eldest male and/or eldest son is often the family's leader, but many families will choose to involve several members so that the onus of difficult decision-making (e.g., DNR orders or removing life support) is not relegated to any one person.<sup>30</sup> One study demonstrated that a few Vietnamese families were familiar with advance directives,<sup>18</sup> so it is likely that many impactful decisions will be left to the family to make, sometimes without consulting the patient. Although this practice conflicts with the Western concept of patient autonomy, it may create less strife within the family unit and may even be in alignment with the patient's (often unspoken, but collectively understood) wishes.

Symptom management is important to many Vietnamese patients, who will often wait to consult a physician until bothersome symptoms appear.<sup>31</sup> Although palliative medicine and hospice may not be familiar entities to most Vietnamese families, medicine as a means of treating symptoms is highly valued. The physician is viewed as a health expert, and families often expect diagnosis and treatment to coincide with the first visit. Physicians who extensively ask questions about symptoms may be viewed as incompetent and stalling for time because they are unable to easily conjure up a diagnosis and treatment.<sup>30</sup> Both active and passive aids in dying are commonly seen as equivalent to killing; however, there are specific circumstances in which the dying process might be more acceptable, including when the medical team has exhausted all appropriate treatments, in which case, many families would expect that the dying process be a comfortable and dignified process.<sup>18</sup>

For Vietnamese Buddhists, the age of the patient may influence how their prognosis is viewed. Illness is an expected part of old age, but in middle age, it may be seen as karmic retribution for past misdeeds.<sup>30</sup> Although Vietnamese people understand infection can lead to disease, they often view illness as a result of multiple spiritual and internal factors.<sup>30</sup> Because of this, religion plays a significant role throughout a patient's illness, particularly toward the end.



**Caregiving and Caregiver Stress**—Because Vietnamese culture is hierarchical and male-dominated, caregiving is a role female family members are expected to fill.<sup>13</sup> This is a role family members are often proud to play and is not traditionally viewed as a burden.<sup>32</sup> Adults are expected to completely take on every responsibility inherent in caring for a sick family member (who is expected to be pampered with daily baths and meals). Caregivers are viewed as a major source of emotional support, which can entail listening to and telling stories from the past (often avoiding death and dying as topics of conversation) and providing religious/spiritual support. Although most hospices offer these services, caregivers may be hesitant or unlikely to seek out such help.<sup>33</sup> Caregiving is traditionally done at home, and placing a relative in a nursing home or other institution is often viewed as disrespectful and to be avoided if possible.<sup>13</sup>

The needs of the seriously ill or dying family member are placed above the needs of the caregiver, which can lead to expected stresses and difficulties, particularly in homes where the women are employed.<sup>33</sup> Caring for a dying relative is often a time-consuming and challenging task, but with a multitude of cultural expectations placed on the caregiver, it is not surprising that stress and burnout are common occurrences in Vietnamese caregivers. Many caregivers will experience anxiety and guilt when they feel as though they are not fulfilling the needs or expectations of their ailing loved one. To vocalize these feelings may be seen as disrespectful or uncaring, and so many caregivers will endure “silent suffering.”<sup>31</sup> There is often a perceived need for privacy and confidentiality, which may prevent caregivers from seeking outside help and resources.<sup>32, 33</sup>

Food is a crucial feature of caregiving in Vietnamese culture and is a tangible way for care to be displayed and received.<sup>33</sup> Vietnamese food is thought to be a critical component of contentment and well-being and has symbolic and spiritual implications as well. This can be problematic in the case of a terminally ill patient, who may not want or require the same amount of nutrition as a healthy person. It can be difficult for caregivers to come to terms with this, as providing meals is often a source of comfort for both patient and caregiver.<sup>32</sup>

It is important to note that many of these caregiving traditions are more closely followed in Vietnam than they are in the U.S., where both spouses often work and where children may feel more entitled to autonomy.<sup>33</sup> Every Vietnamese family may have a different balance of Vietnamese and Western cultures and traditions, and incorporating these into the care plan should always be encouraged.

**Attitudes Toward Autopsy and Organ Donation**—Buddhists believe that death is the final destruction of the body and after death, the soul is reborn. Because death heralds the end of that particular body, there is no specific prohibition against organ donation or autopsy in Buddhism, but these practices may be met with some resistance if not explained properly.<sup>18</sup> The fear of being reborn without the donated organ has been expressed by some Vietnamese patients.<sup>18</sup> Families may also fear reproach from their community if they allow a loved one’s organs to be donated, as it may lead to that family member searching for their missing organ in the afterlife, preventing a peaceful passing.<sup>34</sup>

Some Buddhist families may find maintaining “body integrity” more important than others, depending on their interpretation of Buddhist traditions.<sup>34</sup> Having conversations with family members about organ donation may be difficult as well, as discussing death is often taboo.<sup>34</sup>

Although spirituality is important to many Vietnamese people, the largest barrier to organ donation in this population is likely not based on any particular spiritual or religious practice but is instead an issue of education and understanding. Although knowledge and opinions surrounding organ donation in the Vietnamese American population may vary, misconceptions surrounding organ donation were common.<sup>35</sup> About half (53.4%) thought organs would be sold for money, whereas those who had more correct knowledge surrounding organ donation and transplantation were more likely to be donors.<sup>35</sup>

**Predeath Rituals in Caring for the Dying**—Predeath rituals may vary by religious beliefs and local customs, but all acts revolve around the concept of family. During the last phases of life with a terminal illness, the family plays a central role and is often consulted for all major health care decisions. This is particularly true when there are decisions regarding the cessation of life-sustaining treatments where extensive family discussion may be required. Although direct communication of prognosis may require negotiation, once a terminal prognosis is finally accepted by the family, plans for health care support and caregiving may be discussed. Depending on religious beliefs, a monk may be requested to chant or pray at the bedside or a Catholic priest may be requested for last rites and communion at the end of life.

Death at home or in an institutional setting such as a hospital may depend on family beliefs, but many families have an aversion to death in the hospital as there is a belief that souls of those that die outside of the home may wander with no place to rest, which may bring bad luck to the family.<sup>23</sup> At home, immediate and close family members often take turns caring for the terminal loved one, often sending word to other family members to come and say goodbye. It is common for family members to cook favorite dishes, knowing that the dying person may or may not have the strength to consume the meal. Young family members, particularly children, often show love by demonstrating how good they were or how well they did in school. This coming together of food and family often allows the family time to grieve and prepare for the actual death.<sup>36</sup>

**Postmortem and Aftercare Practices: Funeral, Burial, and Memorial Services**—Some aftercare practices in Vietnamese culture are similar to Western practices, particularly those who practice Catholicism, although there are some distinct differences. After death, the family may wish to stay with the deceased for some time. Prayer and/or chanting may occur immediately after death. For many families, the last hours of life are a crucial time to allow the dying person to settle down and prepare for rebirth. Wakes and funeral mass are common among Catholic families. Memorial services may be held at a Buddhist temple, Church, or funeral home, and family preferences typically dictate cremation or open versus closed casket services. In preparation for the funeral, the body is meticulously washed and dressed. In more traditional families, this task may be performed by the closest family members. Traditional Vietnamese death rituals include placing a grain

of raw rice within the mouth of the deceased (feeding) or potentially a tiny fragment of gold, and tea or coffee is placed in the casket.

Reburial has also been practiced where after several years, the bones of the deceased are exhumed, washed, and placed into a sacred jar for reburial.<sup>37</sup>

In contrast to the U.S., white is the color of mourning. During memorial services, immediate family members may sit or kneel close to the casket and wear all white clothing to include either a white headband or hood. Guests typically wear dark clothing with white headbands, although white armbands are sometimes used. Family members are expected to perform specific rituals, whereas incense is burned and chanting occurs. Internment near other family members is preferred, with ashes sometimes sent to Vietnam to be buried in proximity to other family members. Often monks, spiritual guides, or astrologers may be sought to determine specific date, time, and place of burial to ensure the greatest chance of luck. In the U.S., traditional rituals or ceremonies may be simplified.

**Grief and Bereavement**—Although cultural norms may vary somewhat, the expression of grief is often open and strong with weeping and wailing common among close family members. For some Buddhists, strong emotional mourning during prayers may be considered inappropriate as it may prevent the spirit from transcending. Regardless of religious practice, many Vietnamese Americans believe that expression of strong emotions during the walk to and moments before the burial demonstrates respect and lends importance to the deceased. Although not commonly done in the U.S., in Vietnam, it was common to hire mourners to join the burial procession to emphasize the deceased's importance. In addition to grieving the deceased, funerals are often family events with an emphasis on reunification and feasting with the knowledge that the deceased will join familial ancestors.

Mourning by the family members of the deceased occurs for several days after death (typically three days), with special observances at 49 days, 100 days (tốt khốc or “end of tears”), one year, and two years after death, although the mourning period may be up to three years.<sup>36</sup> More traditional older Vietnamese Americans may wear a black armband to mark the mourning period. The anniversary of the death, called *ám giỗ*, is typically celebrated rather than the birth of the individual and is often treated as a festive occasion or holiday. The yearly private ritual is the responsibility of the senior patrilineal descendant and is attended by close family members.

Food usually centers the celebration with traditional desserts and other favorite foods of the deceased that are prepared and arranged at an altar, which is accompanied by prayer, incense, and other rituals.

**Recommendations for Improving Care of Seriously Ill Vietnamese Americans' Use of Culturally Tailored Assessments**—Effective and culturally competent care at the end of life requires adequate assessment tools. Tools that either diagnose psychosocial distress or psychiatric illnesses or tools that measure symptom burden are highly desirable. However, robust research has been lacking in creating validated tools that are directed toward addressing the needs of older Vietnamese patients at the end of life, particularly in

those who have limited English skills and lower education levels. Most tools have not been adequately translated into Vietnamese or adjusted for cultural beliefs and behaviors. Still, there are several validated tools available to clinicians that were either created specifically for the Vietnamese population or can be successfully adapted. It is recommended that clinicians utilize these assessments to better identify symptoms of serious illness within Vietnamese patients that can be addressed in a culturally appropriate manner.

The Vietnamese Depression Scale (VDS) was introduced in 1982 and is still widely used to identify depression in the Vietnamese population. The VDS is a 15-item instrument that describes the affective, cognitive, and somatic experiences as it relates to depression within the cultural context of the Vietnamese population.<sup>38</sup> The Phan Vietnamese Psychiatric Scale was a pioneering study that used a 26-item depression subscale, 13-item anxiety subscale, and 14-item somatization subscale to better assess psychiatric distress in a culturally sensitive way.<sup>39</sup> The VDS and Phan Vietnamese Psychiatric Scale were both derived from Vietnamese idiom and cultural understandings of both emotional and psychiatric distress. The Vietnamese Symptom and Cultural Syndrome Addendum added a supplemental approach to standard measures of psychopathology by emphasizing somatic symptoms.<sup>40</sup> Several studies have demonstrated successful Vietnamese translations of established symptom assessment tools including the Edmonton Symptom Assessment Scale (ESAS) and European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30.<sup>41, 42</sup> One study was also able to show that measuring English proficiency using the English proficiency subscale of an established acculturation scale for Southeast Asians was significantly correlated to degree of symptom burden.<sup>41, 43</sup>

### Caregiving

There is a fear and misconception among elderly Vietnamese Americans that institutionalized care in a nursing home or assisted living facility implies abandonment from their children. Many are worried about isolation particularly in unfamiliar settings with caregivers who are strangers who do not speak their language, eat the same foods, or share similar cultural understanding.<sup>44</sup> Once the terminal nature of the illness is accepted by the patient and family members, there is a general preference for home-based health and psychosocial services. Even with these additional services, the care of the elderly and frail is still believed to be the responsibility of the immediate family with an expectation that Vietnamese American women will be the dominant caregivers. However, intergenerational conflict can occur when the traditional cultural concept of extended families is broken down and there are significant differences in acculturation. Children of elderly Vietnamese are typically middle-aged with children of their own and struggle to balance the traditional responsibility to care for elders with more contemporary Western roles in which more than one person may be working outside the home, which may add stress and anxiety to caregiving roles.<sup>44</sup> Besides, language and cultural differences between the generations may exacerbate these tensions.

For clinicians and support services, offering linguistic, transportation, and day care services may alleviate both the physical and emotional distress that both the patient and their family may be experiencing. Focusing on the family unit and personal stories as they relate to

traumatic experiences such as the Vietnam War and understanding unique coping mechanisms may help contextualize care plans.<sup>45</sup> Home care should be culturally appropriate and meet the needs of the elderly and frail as well as the family caregivers. It is also important to cultivate relationships with community senior centers and religious organizations that cater to Vietnamese populations as many older Vietnamese tend to find support within these institutions.

### **Hospice Care**

When the terminality of the patient's illness is accepted, family members and people in the community often want that person to die peacefully and comfortably. Most terminally ill elderly prefer to die in the home surrounded by family, rather than in institutionalized settings such as hospitals or nursing homes. Hospice can often provide complementary caregiving alongside the family and is embraced by both patients and family members. Hospice agencies should be aware of the unique cultural differences in differing generations and be prepared to offer comprehensive culturally and linguistically appropriate home care services.

### **Use of Interpreters**

In line with best practices, using certified Vietnamese interpreters to explore attitudes, hopes, and potential paths forward is recommended. Unless specifically desired by the patient, the use of relatives to interpret can result in unintended consequences such as medically inaccurate statements and exacerbations of intergenerational conflict surrounding death and dying.

Consistent with previous studies, it can be helpful to approach the interpreter before starting the meeting to determine their level of comfort with what will be discussed and to allow them time to prepare. The process of setting the stage may also allow time for the interpreter to share their insights into potential incongruences with cultural norms or expectations. Advanced preparation can be especially helpful in those communities with smaller Vietnamese populations as the interpreter may have an established relationship with the patient. In addition, despite evidence that debriefing is beneficial to the long-term health of palliative care teams, inclusion of the interpreter after a family meeting is relatively rare despite reports indicating that they experience strong emotions and discomfort that persisted after the end of the meeting.<sup>46</sup>

### **Conclusion**

Clinicians providing health care services to the Vietnamese American population should be aware that although there are many shared cultural experiences, given the differing levels of acculturation, health care decisions surrounding serious illness or end-of-life care may vary from patient to patient or even vary among members of the family unit itself (Table 1). Empathic and culturally effective care depends on recognizing the challenges with caring for this population and understanding that each patient's lived experiences will contribute to complex decision-making. Health care providers should either partner with Vietnamese community organizations or structure culturally appropriate programs that take into account

this variability. Taking the time to define, create, and implement these types of programs will narrow the health care gap and improve the care of seriously ill or terminal Vietnamese American patients.

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**Table 1.**

**Real Cases of Seriously Ill Vietnamese Americans That Illustrate Cultural Beliefs and Behaviors**

Learning Points	Care Description
<p>Older Vietnamese may strongly believe in native healing practices. Their beliefs may be in conflict with highly educated younger generations.</p>	<p>H.T. was a 55-year-old Vietnamese woman who immigrated to the U.S. in the 1980s. She had a history of stage IV non-small cell lung cancer and history of venous thromboembolic events on full-dose anticoagulation who presented to the hospital with left-sided weakness and fatigue and had an MRI of the brain that showed extensive bilateral acute infarcts with high-grade occlusion of the proximal right middle cerebral artery. The prognosis was estimated at hours. There was disagreement between the husband and the two adult children over how end-of-life care would proceed. The husband wanted to pursue indigenous therapies, whereas the children wished to have a second opinion at another academic institution. A Vietnamese interpreter who was also a cultural leader was eventually engaged. After multiple family meetings that also included religious and community leaders, it was decided to initiate terminal care in the hospital. When the patient did not pass immediately and the team stated that the anticipated prognosis was in the range of days to week, the husband stated that he wished to bring his wife home. Hospice services in conjunction with a local Vietnamese advocacy group helped arrange care services for the home. The patient was discharged home and died two weeks later.</p>
<p>The patient's culture can greatly impact the clinical manifestation of their illness(es).</p>	<p>P.N. was a 60-year-old single Vietnamese man with history of hepatitis B and associated cirrhosis with typical complications of end-stage liver disease. He presented to the hospital with severe abdominal pain different from his usual pain associated with tense ascites. CT scan of the abdomen revealed a large necrotic liver mass suspected of being hepatocellular carcinoma. There was also concern that the mass was also bleeding, which resulted in multiple packed red blood cell transfusions. Although the patient was in severe pain, he refused pain medications. Despite multiple meetings during which the care team engaged a Vietnamese interpreter and attempted to convey that the patient was seriously ill with a limited life span, the patient continued to escalate his demands for life-prolonging medical treatments. A palliative care consult was eventually initiated to assist with psychosocial support and symptom management. A junior member of the palliative care team spent time exploring the patient's life experiences instead of focusing on any medical issues. The clinician discovered a rich history about the patient's service in the Vietnam War and identified that the patient's symptoms were likely due to post-traumatic stress disorder. A Vietnamese social worker, who practiced approximately 50 miles from the institution, was recruited to assist the team in exploring the patient's past. Utilizing telehealth video technology, multiple meetings were held to give the patient an opportunity to do legacy work. After a week, the patient agreed to be transferred to an Asian centric subacute facility with local hospice support. He died a few days later.</p>
<p>Whereas many patients may long for their homeland of origin, others may not.</p>	<p>C.B. was an 82-year-old Vietnamese man who was brought to the emergency department for evaluation of weakness, weight loss, and bloody urine. He lived in an assisted living facility and was largely self-sufficient requiring only minor supervision. His granddaughter who lived locally would visit him weekly and bring him his favorite traditional foods. During the hospitalization, he became septic and required admission to the intensive care unit. Given the lack of significant clinical progress, the palliative care team was consulted to help define the patient's goals of care. The granddaughter informed the palliative care team that in Vietnam, her grandfather had been famous for fortune telling and had always been an entertainer in social contexts. She explained that her grandfather's vibrant personality and love of life would not allow him to accept a quality of life that did not include the ability to interact with other people. He had also served in the Vietnam War as an officer and first settled in Texas before eventually moving to California. Given negative experiences that the patient had in Vietnam, the granddaughter shared that her grandfather had instructed her to keep his body in the U.S. as he had vowed never to go back to Vietnam. He also hoped that he would be reborn as an American in his next life. The granddaughter consulted her mother who was living in Australia and together they decided not to escalate care. He eventually died in the hospital.</p>
<p>For some families the preferred place of death may be the hospital.</p>	<p>S.N. was a Vietnamese American man who was born in the U.S. to immigrants who fled after the Vietnam War. He suffered from advanced renal disease, which was originally diagnosed as a young child and depended heavily on his family for support and care. By 31 years of age, he had spent many years on dialysis and had exhausted most of his options for hemodialysis access because of multiple graft infections. When he was admitted to the hospital, he was found to be in heart failure due to a large vegetation on his mitral valve but was deemed not to be an operative candidate. The family was devoted and drove several hours each day to visit him, believing that if they waited long enough, he would get better. Over time, he accepted his prognosis and unilaterally decided his quality of life was very poor and that he wanted to go home to die. As one of his last wishes, he also wanted very much to visit his paternal grandmother before he died to pay his respects. His sister was willing to support his choice and provide primary caregiving for him in the home, but his brother and stepfather would not give permission. After multiple family meetings and extensive discussion, the family conflict could not be resolved and they informed the team that the patient had changed his mind and that he now wanted to die in the hospital. The patient became withdrawn and disengaged emotionally from the care team and died the following day.</p>

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