Understanding Hmong Elders' Care Preferences for the Dying Process

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ABSTRACT

Hmong elders, who moved to the United States as political refugees from Southeast Asia have sought to maintain their cultural traditions and find that having those traditions honored at end of life (EOL) may prove to be difficult. This difficulty arises from healthcare providers having limited knowledge on providing culturally sensitive EOL care to Hmong elders. The dearth of knowledge contributed to Hmong elders experiencing a dying process that is not culturally sensitive (Culhane-Pera, 2003a). Additionally, acculturation and intercultural adaptation could impact traditional methods of EOL care. The religion, spiritual beliefs, and spiritual rituals that Hmong elders have and practice could also influence their EOL care preferences. This qualitative study sought to explore Hmong elders' care preferences for the dying process with regard to their acculturation, intercultural adaptation, religion, and spiritual beliefs and practices.

Semi-structured interviews conducted with 30 Hmong elders who were not terminally ill explored their acculturation strategies and care preferences for the dying process. Transcripts were analyzed via conventional and directed content analysis with Berry's acculturation typology (1997; 2005; 2015) and Ward's intercultural adaptation framework (2001) guiding the directed content analysis portion.

Findings were related to Hmong elder participants' EOL care preferences with regard to the physical, psychosocial, and cultural care domains. Directed content analysis resulted in four categories of acculturation strategies: separation, separation & integration, integration, and integration & assimilation. Results suggested that some participants have adapted psychologically and socioculturally, while others have not. Participants reported some adaptations in response to their adult children's adaptations. Christian participants believed in

prayers as part of their EOL care and preferred to receive prayers. Animist participants spoke of soul loss and preferred spiritual rituals such as soul calling to be conducted. Participants also recognized the impact of the Western culture on their traditional caregiving methods. Findings have practice, policy, and research implications. Social workers and healthcare professionals should ensure that culturally sensitive assessments and care are provided to Hmong elders. Policies should promote culturally sensitive services for Hmong and other refugees and immigrant communities. Future research should include interviews with Hmong adult children as they are most likely the preferred caregivers.

CHAPTER 1: INTRODUCTION AND PROBLEM STATEMENT

Evidence shows that Hmong elders immigrating to the United States (U.S.) as refugees from Southeast Asia may not be receiving the care they prefer at the end of life (EOL) (Culhane-Pera, 2003a; Culhane-Pera, 2003b), which could result in a low-quality dying process. Currently, little is known about care preferences Hmong elders regard as contributing to quality of life during the dying process. This dearth of knowledge is problematic as researchers suggest that quality of life may be challenged when healthcare providers lack understanding of a patient's preferred care (Wright et al., 2008). Balboni et al. (2007) found that quality of life during the dying process improved for White, African American, and Hispanic terminally ill patients who received their preferred EOL care, particularly with regard to their spiritual needs. For providers caring for immigrant patients such as the Hmong (Barrett et al., 1998; Pinzon-Perez, 2006), many layers of complexities exist in that acculturation and adaptation to U.S. societal norms, as well as religion and spiritual beliefs and practices, may influence Hmong EOL care preferences. Thus, it is important to garner an understanding of Hmong elders' care preferences and how acculturation, adaptation, religion, and spiritual beliefs and rituals influence these preferences.

Acculturation refers to the changes that individuals make as a result of immigration, colonization, or other forms of intercultural interactions in order to adapt to their host culture (Berry, 1997, 2005, 2015). For Hmong elder refugees, who have immigrated to the United States in several waves over the past 45 years, it is likely that they have acculturated in different ways. According to Sam and Berry (2010), two issues are considered when people acculturate: the extent to which people maintain their primary culture, and the level to which they wish to have contact with the larger society or host culture. Berry (1997, 2005, 2015) proposed four acculturation strategies that people may adopt: assimilation, integration, separation, and

marginalization. Assimilation refers to the strategy that people use when they do not want to keep their primary cultural identity and identify closely with aspects of their host culture. The integration strategy is used by people who want to maintain their primary culture while having daily interactions with people from their host culture. Separation involves maintaining one's original culture and minimizing interactions with people of the host culture. Finally, marginalization describes people who have little interest or possibility of keeping their original culture and have minimal interest in interacting with others of their host society and their own culture– both of these often occur due to reasons of "enforced cultural loss…or reasons of exclusion or discrimination" (Sam & Berry, 2010, p.476). These acculturation strategies are not fixed nor are they outcomes. In fact, people can acculturate through different strategies based on situational factors such as environmental influences (Sam & Berry, 2010). For example, people may exercise more cultural maintenance (separation) in private settings that include family or extended relatives and use integration in places that involve more people of the host culture, such as their workplaces (Berry, 1997). The four acculturation strategies are just that, strategies, and not end results of people's intercultural exchange. The outcome of acculturation is intercultural adaptation, which are the stable changes that people or groups make in response to the demands in their environment (Berry, 2015). The acculturation strategy people employ has been found to be associated with how well they adapt to their host society (Sam & Berry, 2010).

Based on the acculturation strategy people use, they adapt by making relevant changes (Sam & Berry, 2010). Intercultural adaptation is defined as the psychological well-being and sociocultural management that people gain based on their acculturation strategy (Berry, 1997; Sam & Berry, 2010). Psychological well-being is the feeling of being satisfied as a result of an individual's adaptations, while sociocultural management refers to the individual's behavior and

ability to “fit in” or have interactions with others in the host environment (Ward, 2001, p.414). Researchers have determined that people’s acculturation strategies and resulting intercultural adaptations they make can give rise to different psychological well-being and sociocultural management outcomes. Integration strategy has been found to be the most adaptive with better psychological and sociocultural outcomes compared to the other three strategies (Liebkind, 2001; Sam et al., 2008). The marginalization strategy has been found to result in low intercultural adaptations because it consists of lack of support from any cultural group (Sam & Berry, 2010)

In terms of acculturation studies within the Hmong community, Lee and Green (2010) found the acculturation strategies used by a sample of 110 Hmong, ages between 18 and 51 years old, who immigrated to Wisconsin, differed. The Hmong participants were more integrated than they were assimilated, separated, or marginalized. The participants who identified with integration were those who came to the United States at a younger age and could speak, read, and write well in English. The participants who identified with the separation strategy were those who came to the United States at an older age and could not speak, read, or write well in English. Those who assimilated were not only able to speak, read, and write well in English but they also preferred to communicate in English than in Hmong. For the Hmong participants who were more marginalized, they felt that they could neither trust nor communicate with anyone and that other people could not understand them. Lee and Green asserted that the more separated or assimilated the participants were, the more likely they would be marginalized because they would not identify with either the Hmong or mainstream American culture (separated) or would not understand the Hmong culture and language (assimilated). They also posited that the Hmong population will likely become more assimilated as they continue to live in the United States and may eventually be unable to understand their Hmong culture and language (Lee & Green, 2010).

The differing acculturation strategies and the threat of younger Hmong becoming more assimilated than Hmong elders could serve as barriers for Hmong elders receiving the traditional EOL care they desire.

Consideration of the acculturation strategy of Hmong elders and of their children, as well as the resulting adaptations, is important when seeking to understand how elders may be cared for in later life and during their dying process. The Hmong have a traditional way of caring for elders. Back in their home country, the eldest son and his wife are responsible for providing care to the son's aging parents, with the wife (daughter-in-law) being the primary caregiver (Gerdner et al., 2008). This tradition of providing care for elders worked well as Hmong families lived near one another and worked on one farm. This lifestyle, however, has been challenged by the U.S economy, which has resulted in adult children having to adapt to working outside of their homes and/or living in separate dwellings from their elder parents due to job relocations (Gerdner et al., 2008). These adaptations made by Hmong adult children have led to changes in traditional approaches to caregiving for elders in that they often no longer have the capacity to provide care for their elders at home (Culhane-Pera, 2003b; Gerdner et al., 2008). This adaptation has been especially difficult for daughters-in-law, because they find themselves having to work outside of the home in addition to having the responsibility of being caregivers (Gerdner et al., 2008). Furthermore, gender roles have also been found to play an important part of the elder's care in terms of male and female caregivers' responsibilities (Her-Xiong & Schroepfer, 2018); however existing evidence suggests that this adaptation has influenced these traditional gender roles as well (Culhane-Pera & Xiong, 2003). Hmong women's roles tend to revolve around domestic duties such as cooking and cleaning (Her-Xiong & Schroepfer, 2018), whereas men tend to be more responsible for making decisions on behalf of family members.

Researchers, however, have asserted that some Hmong women and young adults now tend to make their own decisions and for the most part, the family members, elders, and clan leaders are respecting these decisions (Culhane-Pera & Xiong, 2003).

Another layer of complexity related to the provision of care to Hmong elders during the dying process is the elder's religion and spiritual beliefs and practices. The two most practiced religions for Hmong in the United States are Animism and Christianity. As of 2006, about 70% of Hmong living in the United States practiced Animism and ancestral worship, while approximately 30% practiced some form of Christianity (Lee & Tapp, 2006). For Hmong, the concept of spirituality is related to the animism belief of a spiritual world existing alongside the physical world (Bliaout, 1993; Cha, 2003; Cha, 2014; Plotnikoff et al., 2002). Individuals have souls and inanimate objects possess spirits, and constant interactions take place between the spiritual and physical worlds for life to be balanced. This definition of spirituality differs from the definition that is commonly found in mainstream healthcare services such as palliative care. Spirituality in palliative care is the way humans pursue and express the meaning and purpose of life as well as connect to oneself, nature, other people, and to the sacred (Puchalski et al., 2009).

The complexity of how religion and spiritual beliefs and practices may impact Hmong elders' EOL care may be further understood by Her-Xiong and Schroepfer's study (2018). The researchers found that the preferred care at EOL reported by Hmong elder participants was influenced by their religion. For example, Hmong elders practicing Animism believed that Shamans would need to perform certain rituals, while practicing Christians believed in the power of prayer. The rituals that Shamans would perform include that of soul calling and spiritual offering. Both rituals can be performed during a terminal illness as attempts to cure sick individuals. A soul calling is performed when an individual's soul is believed to have left its

owner's body, thus causing the sickness. A spiritual offering can be performed when someone does not become better after a soul calling. A spiritual offering involves a shaman making animal sacrificial offerings to the spirits that govern the land to forgive the sick individuals and to give their souls back to their physical body. Similar to the Animists' beliefs in certain rituals being performed, Christians believe that prayers were needed during this time. They believed that prayers would make terminally ill individuals feel happy and that the fate of their illnesses was dependent on God (Her-Xiong & Schroepfer, 2018). Clearly, a Hmong elder's religion and spiritual beliefs are important to consider when seeking to understand Hmong elders' care preferences for their dying process.

For healthcare professionals providing Hmong elders with EOL care, available evidence does suggest that their lack of knowledge about Hmong care preferences could result in the unintended delivery of culturally insensitive care that could negatively impact the elder's dying process (Culhane-Pera, 2003a; Gervais, 2003). In a case study of a Hmong elder using hospice care services, the nurses misunderstood the family's way of providing care for the patient (Culhane-Pera, 2003a). The nurses felt that the family's behavior of encouraging the elder to eat and drink even though she was in a coma was the family being in denial of the elder's pending death. On the other hand, the family viewed the nurses' actions of encouraging the patient to let go and pass away as harmful and dangerous. The family regarded the nurses' actions as having cursed the elder (Culhane-Pera, 2003a) based on two beliefs. The first is that talking about dying and death, especially to a terminally ill elder, is a major taboo in the traditional Hmong culture (Vawter & Babbitt, 1997). The second is that family members should respect the elder by doing everything they can to cure the elder (Vawter & Babbitt, 1997). Lack of understanding regarding these beliefs served as a barrier for the nurses seeking to provide a quality dying process.

With evidence from prior literature suggesting challenges for Hmong elders to receive culturally sensitive care during the dying process and healthcare providers lacking information to provide such care to these elders, research is necessary to attempt to elucidate the care preferences that may be helpful in addressing this gap. The purpose of this study is to garner an understanding of 1) the physical, psychosocial and cultural preferences Hmong elders deem as essential to a quality dying process, as well as 2) how acculturation, adaptation, religion and spiritual beliefs and practices may influence these preferences. Improved understanding would serve to enhance healthcare providers' awareness of the heterogeneity within the Hmong community, and enhance the possibility of Hmong elders experiencing a culturally sensitive dying process.

CHAPTER 2: LITERATURE REVIEW

This chapter will review four key areas related to studying Hmong preferences for care at EOL: Hmong history as it relates to their arrival in the United States; current knowledge of Hmong elders' care cultural beliefs and practices related to the dying process; role of Hmong elders' religion and spiritual beliefs with regard to their care preferences; and the influence of acculturation and adaptation on Hmong cultural practices, specifically with regard to EOL. It should be noted that the review of elders' care preferences for the dying process revealed few studies on this topic. Researchers have examined cross-cultural issues that arose through Hmong elders' encounters with the Western healthcare system during their dying process (Culhane-Pera, 2003a; Gervais, 2003); values and beliefs regarding Hmong elders' EOL care decision-making (Ford & Moldenhauer, 1998); Hmong beliefs with regard to providing care for someone at EOL (Her-Xiong & Schroepfer, 2018; Helsel et al., 2019); and Hmong's perceptions on mainstream EOL care services (Lor, 2017). Although few in number, these studies do make important

contributions to understanding the EOL care preferences of Hmong elders' who have immigrated to the United States.

The Secret War

The history of Hmong has been traced to China (Bliatout, 1993; Cha, 2014; Culhane-Pera & Xiong, 2003; Michaud, 1997), where they lived in the mountainous regions and led an agrarian lifestyle (Cha, 2014). Due to political issues with the Chinese government, some Hmong immigrated south to Southeast Asia and continued living an agrarian lifestyle mainly in the northern parts of Vietnam, Laos, and Thailand (Vang, 2010). While living in Southeast Asia, the Hmong in Laos and Vietnam became involved with the United States during the Vietnam War.

During the Vietnam War, the United States Central Intelligence Agency (CIA) recruited the Hmong to fight against the communist regimes in Laos. The United States' involvement with Laos was meant to be a covert operation (Vang, 2010). The CIA were interested in the Hmong because of their knowledge regarding the northern mountainous regions of Laos and because of their ability to fight as guerillas in jungles and as regular troops in positional warfare (Chan, 1993). As part of the recruitment, the Hmong and the CIA made an agreement that if the communists were successfully prevented from entering Laos, the CIA would help the Hmong to sustain their lives in Laos. If, however, the communists did invade Laos, the CIA would find a new home for the Hmong after the war (Hamilton-Merritt, 1993). This operation became known as the Secret War.

In 1973, the United States withdrew from the Vietnam War due to peace talks and cease-fire agreements and many of the Hmong, who were allies with the United States, were left behind (Chan, 1993; Warner, 1995). They fled Laos to avoid persecution from the Lao government and many attempted to cross the treacherous Mekong River to seek asylum in

Thailand. Although thousands achieved refugee statuses, countless Hmong died during the escape due to injuries, malnutrition, drowning, and other disasters (Culhane-Pera & Xiong, 2003). Few Hmong (mainly Hmong military personnel and their families) who were initial recipients of the United States' promise, arrived in the United States in 1975 (Vang, 2010). It was not until 1976 that the United States upheld its promise to provide the Hmong with a new home through the Indochina Migration and Refugee Assistance Act. The act was enacted in 1975 to support refugees fleeing Vietnam and Cambodia; however, the extension to Laotians and, ultimately, Hmong refugees, did not occur until 1976 (Vang, 2010). Since 1975, more than 200,000 Hmong refugees have fled Laos, with about 90% of them resettling in the United States (Yau, 2005).

Cultural Beliefs & Practices

The literature review revealed six Hmong beliefs and practices that are important to consider at EOL. The first belief is that it is taboo to speak about death and dying. The second belief is that all attempts must be made to try and cure a person who is terminally ill. A third belief is that family are to provide care for the individual, perform domestic duties, make decisions, and keep constant vigils around the terminally ill. These acts of care speak to the collective practice of the culture. Fourth, Hmong have different beliefs regarding pain expression and taking medications during the dying process (Vawter & Babbitt, 1997). Fifth, final wishes during the dying process are important to Hmong elders because they assure that their children knew their love for them. Finally, the importance of being clothed upon death is an important belief because Hmong believe that whatever the individual wears at death, they will wear it to the next life. In this section, these beliefs will be discussed in depth.

Taboo to Speak of Death and Dying

Not talking about death and dying directly to terminally ill individuals, especially elders, is an important Hmong belief, which is practiced in order to convey respect and compassionate treatment of the terminally ill (Gerdner, 2010; Gerdner et al., 2006; Vawter & Babbitt, 1997). Researchers found that Hmong prefer to speak about death and dying indirectly. For example, instead of saying "Your mother is dying", Hmong prefer to say "Your mother is not doing well" (Vawter & Babbitt, 1997). Hmong believe that words have powerful meaning and such directness is believed to cause evil spirits to bring death prematurely.

Exhausting Treatment Options

Another Hmong belief is that exhausting all treatment options in attempt to cure a terminally ill elder is the way to show them respect (Vawter & Babbitt, 1997) and to prolong the patient's life so that all family members, near and far, could be present in the decision-making process (Helsel et al., 2019). Hmong family members honoring this belief would seek life-sustaining interventions no matter how invasive.

In honoring this belief, traditional Hmong have been found to prefer the use of non-Western medicine, such as herbal (Cha, 2003; Culhane-Pera, 2003a; Her-Xiong & Schroepfer, 2018) and Chinese medicine (Culhane-Pera, 2003b). Although the use of herbal medicine is a traditional Hmong treatment modality, the treatment has been used by both Animist (Her-Xiong & Schroepfer, 2018) and Christian Hmong (Culhane-Pera, 2003a). Furthermore, evidence exists that some Hmong Animist (Her-Xiong & Schroepfer, 2018) and Christian Hmong (Culhane-Pera, 2003a) have used a combination of non-Western and Western medicine.

Family Involvement

The need for family members to provide care to their terminally ill loved ones is another key belief (Culhane-Pera, 2003b; Culhane-Pera, 2003b; Her-Xiong & Schroepfer, 2018; Helsel et al., 2019). The types of care reported by researchers included encouraging food and water intake (Culhane-Pera, 2003a), cooking, bathing and holding them (Her-Xiong & Schroepfer, 2018). In addition, providing care to a terminally ill Hmong elder was found to be a group effort. In Her-Xiong & Schroepfer's study, an Animist Hmong elder shared that it can take up to seven or eight individuals to provide care to a loved one who is dying. Helsel et al. (2019) found that although the eldest son and his wife would traditionally be the primary care providers and decision-makers for their seriously ill parent(s), they would receive input and assistance from other family members and clan leaders. Finally, Hmong prefer their family members as caregivers because they believe that caregivers of other races may not know the language, food preferences, and cultural beliefs deemed necessary at this stage (Helsel et al., 2019).

Evidence has also been found regarding the necessity of the family's presence when professionals are providing palliative care to Hmong patients. In a study by Neiman (2019), palliative care nurses reported the strong constant vigilance of family members, which often led to the nurses experiencing some challenges. The nurses felt that the constant presence of family and relatives inhibited their ability to provide medical model care to the patient. The constant presence and large number of family visitors often overwhelmed the nurses in their provision of care to Hmong patients. They noted that family members would continue doing some traditional rituals for the patients. One nurse reported that she was going to reposition a Hmong patient and perform other tasks but had to delay them as soon as she saw the family surrounding the patient's bed doing rituals. Other accommodations made by the nurses included ensuring an appropriate

space for the family to burn incense and assisting the family with dressing the patient in the traditional ancestral death robe (2019).

The need for family and relatives keeping vigil over the elder who is dying is another final wish reported by Hmong elders. The presence of family and relatives during the dying process is important because in order to convey respect to the dying elder, they must keep a constant vigil around the elder's bed and plead with the elder not to die (Culhane-Pera, 2003a; Vawter & Babbitt, 1997). During the vigil, it is important that family, relatives, friends, and community members visit the terminally ill elder to not only pay their respects, but also to listen to the elder's last words prior to dying (Bliatout, 1993; Culhane-Pera, 2003a; 2003b). This practice is important because it is believed that a dying elder's last words provide wisdom and blessings to those who hear them (Culhane-Pera, 2003a). Furthermore, being present during the elder's last breath also means that one will receive luck from the elder, and family members should be the ones receiving this luck (Helsel et al., 2019). This belief may result in many Hmong family, relatives, friends, and community members visiting the terminally ill elder.

Practices Regarding Elders' Preferences for How Care is Given

Related to the importance of family providing care to terminally ill Hmong elders is the role gender plays in how elders' preferred care is given. The Hmong are modest and so prefer same-sex caregivers (Her-Xiong & Schroepfer, 2018; Parker & Kiatoukaysay, 1999). If a mother is terminally ill, her daughter(s)-in-law and daughter(s) would be responsible for providing the care. Similarly, if a father is ill, his son(s) and son(s)-in-law would provide the care for him.

Gender also plays a role in terms of which family members provide the different types of care to their ill loved one. Specifically, research has shown that women are responsible for the domestic work and providing hands-on care to the ill person (Culhane-Pera, 2003a; Her-Xiong &

Schroepfer, 2018). On the other hand, decisions made during the dying process has been found to be the responsibility of the head male figures such as the father, husband, elder sons, clan leader, etc. (Culhane-Pera, 2003a; 2003b; Her-Xiong & Schroepfer, 2018). With this collective decision-making practice done by males in the family, any consequences that may arise from the decisions affect the family as a whole and are dealt with by the decision-makers and family as a unit.

Pain Expression and Medications

In regard to Hmong beliefs concerning how pain is expressed and Western pain medication used, Vawter & Babbitt (1997) found differing beliefs. In their study, some Hmong reported they considered it shameful to express the gravity of their pain, while others felt it was necessary to express their pain in order to convince people of the severity of their illnesses. Furthermore, Hmong elders noted that they may not share their pain with healthcare professionals for three reasons: 1) they expect healthcare providers to be aware of their pain; 2) they fear pain; and 3) they have difficulty talking about it. Elders participating in the study reported that they may prefer to talk about pain in metaphors such as feeling exhausted. In regard to using Western pain medications, some Hmong elders reported taking them, and others that Western medications are too strong for them, do not alleviate their pain, or side effects are unacceptable.

Vawter & Babbitt (1997) found that Hmong's varying beliefs regarding pain expression and taking Western pain medications influence their care preferences during the dying process. Some Hmong in the study choose not to accept pain medications as they believed that enduring their pain would increase their chances of having a better life in the next life. Other Hmong who were seriously ill noted their belief that taking pain medications would prolong their lives, which

they do not want to happen as they wish to die. These pain beliefs may prove challenging in hospice care settings as Hmong patients may not be open to Western pain medications (1997).

How Terminally Ill Elders Communicate to Their Loved Ones

In regard to a Hmong elder's final wishes during the dying process, researchers have gained knowledge about two important practices: communicating love to their children and family standing vigil. In a study by Culhane-Pera (2003b) Hmong elders discussed the crucial practice of communicating love to their children, and historically have done so through verbal communication. In doing so, they noted the importance of assuring their children that they love them. One Hmong elder in the study who was dying from cervical cancer audio recorded her last words to her children, which focused on assuring them that she loved them and asking that they care for one another (Culhane-Pera, 2003b). According to Reid (2007), Hmong elders practice an oral culture such that audio-recording their wishes may be more appropriate and meaningful to them than documenting their wishes on paper (as cited in Gerdner, 2010).

Traditional Clothing

Being clothed in ancestral clothing is believed to be important for a Hmong elder upon their death (Culhane-Pera, 2003; Gerdner, 2010; Her-Xiong & Schroepfer, 2018). Hmong Animists believe that the clothing someone wears at the time of death is what that person's soul will wear when they enter the spirit world (Her-Xiong & Schroepfer, 2018). For Hmong who practice Animism and ancestor worship, they believe that wearing ancestral clothing at the time of death is necessary because the deceased individual's soul will travel to the land of the ancestors, live among them, and interact with the living descendants as ancestors (Culhane-Pera, 2003a). Hmong Animists believe that the journey to the land of ancestors is long and arduous and so wearing these clothing, especially multiple layers of them, will keep the deceased warm

and protected as they endure this journey (D. Cha, personal communication, August 30, 2018). Upon death, the terminally ill individual will wear the unique ancestral clothing, which is similar to what their ancestors wore. Wearing this clothing would signify that the individual is clothed when meeting their ancestors, otherwise they would be seen as "naked" by the ancestors (Her-Xiong & Schroepfer, 2018). Hmong elders also believe that there are ramifications that would occur if the deceased elder does not wear any clothes. Her-Xiong and Schroepfer found that if an elder were to pass away without wearing any clothes at all, the elder's soul would not be able to move to the afterlife and would come back to look for clothing from the living family members. In such a case, the living family members would have to perform a ritual that involves burning a set of clothes to symbolically send to the deceased elder after death (Her-Xiong & Schroepfer, 2018).

Religion & Spiritual Beliefs

Prior evidence suggests that the Hmong community in the United States is heterogenous with regard to their religious beliefs (Barrett et al., 1998; Cha, 2003; Her-Xiong & Schroepfer, 2018). While some Hmong retained their Animist and ancestral worship beliefs, others practice Christianity. Her-Xiong and Schroepfer found differences among Hmong Animists' and Christians' EOL beliefs and rituals. Some Animist respondents were holding firm to traditional beliefs and practices, while others had willingly let go of some. In regard to Christian respondents, some held a mix of Christianity and Animist beliefs and practices, and some believed and practiced only Christianity (Her-Xiong & Schroepfer, 2018). When discussing Hmong EOL beliefs and practices, it is necessary to talk about both religion and spiritual beliefs together because they are so interwoven (Bliatout, 1993), and may differ based on whether the

elder identifies as Animist or Christian. It is, therefore, important to review what is known about Hmong elders' religious and spiritual beliefs.

Hmong Animism

Animism and ancestor worship are beliefs that consist of natural objects having spirits and human beings having souls (Bliatout, 1993; Plotnikoff et al., 2002). These spirits and souls exist in a spiritual realm that co-exists with the physical world; this spiritual realm and spirits living in it are often sought after for well-being purposes and for treatment-related reasons during times of illnesses (Bliatout, 1993; Plotnikoff et al., 2002). For Animist Hmong, spirituality is the existence of spirits and human beings having souls, which influence the individual's physical world.

For Hmong elders who practice Animism and ancestor worship, certain rituals are performed to diagnose, treat, and/or cure illnesses, even if the individual has been given a terminal diagnosis (six months or less to live). For example, rituals such as tying strings around the individual's wrist, soul calling, and spiritual offerings would be done. Culhane-Pera et al., (2003b) presented a case study of a Hmong elder with a brain hemorrhage, who was on a mechanical ventilator. In an attempt to treat her illness, family members sought out a Hmong shaman to tie strings around the elder's wrist so that her soul would stay with her body. Hmong believe that a soul leaving its owner's body can bring illness to the individual (Bliatout, 1993; Her-Xiong & Schroepfer, 2018). In the case study, the family members also sought other spiritual healing practices, one of which involved burning incense in order to communicate with the spirits (Gervais, 2003).

Animist Hmong elders believe that an elder should die in their own home, in a son's home, or in the home of a relative who has the same last name and religion/spiritual beliefs as

that of the elder. The reason for this belief is that these homes house the spirit altar, which is used to appease the household spirits responsible for the welfare of its residents (Bliatout, 1993; Cha, 2003). The spirit altar is a shrine made out of joss paper, which are also known as spirit money used in ancestor worship ceremonies. This altar is located on the wall of the main living area (Lee & Tapp, 2005). It is also believed that after death, one of the many souls that an individual has will remain with their ancestors and protect the living descendants through the family's appeasement (Her, 2005). The altar is a gateway for the living family members to communicate with ancestors who also reside in the house as spirits.

Hmong Christianity

In addition to Animism and ancestor worship, the other religion that is most practiced by Hmong in the United States is that of Christianity (Lee & Pfeifer, 2006). Although traditionally not a religion of the Hmong, Christianity has become a prominent religion in contemporary Hmong culture in the United States and Southeast Asia due to Hmong's conversions as a result of missionaries and church sponsorship to the United States (Lee & Tapp, 2010).

The religious practices of Hmong Christians also play an important role in their dying process (Culhane-Pera, 2003a; Her-Xiong & Schroepfer, 2018). Her-Xiong and Schroepfer found that Hmong Christians in their study believed praying would make the person who was dying feel happy and that the fate of their illness depended on God. Hmong Christians also shared that Christianity was a way of life for them and that their Christian beliefs provide guidance on what to do at EOL, as well as assurance as to what would happen after death. They believed that when they passed away, their spirit would go be with God (Her-Xiong & Schroepfer, 2018). In addition to prayer, having a priest visit during the dying process to give last rites was also deemed to be important (Culhane-Pera, 2003a).

In theory, once a Hmong is a Christian, it is impossible for them to participate in social activities hosted by Animist Hmong family members, such as weddings and funerals because the activities are spiritual in nature (Lee & Tapp, 2010). This restriction is due to Animism being heavily involved with the spiritual realm. Hmong Christians who fall into this category are therefore forced to cut ties with their family members who still practice Animism (p. 42).

Evidence, however, exists that there are varying degrees as to how firm a Hmong Christian is in terms of their belief in spirituality as defined by Hmong Animists (Gerdner, 2012). Although some Hmong Christians' beliefs are quite rigid in that it restricts them from doing activities related to their Hmong family members who are not Christians, other Christians hold a mix of both belief systems. In a study of Hmong elders' use of Shamanism practices during their chronic illnesses, Gerdner (2012) found that some Christian Hmong elders believed in the impact of the spiritual world on their daily lives, health, and healing practices. One elder shared that she believed her soul was not doing well, which caused her illness and thus led her to pray for healing. This knowledge indicates that Hmong partake in different religious and spiritual practices based on their religion, and these choices have implications for their health, healing, and EOL care practices.

Acculturation

In addition to the importance of religion and spiritual beliefs and practices, it is necessary to understand the influence of acculturation and adaptation on Hmong cultural beliefs and practices, most specifically with regard to EOL. Acculturation is a phenomenon that researchers believe to be a dual-process, which means two or more cultural groups, usually one dominant and another non-dominant, change psychologically and culturally as a result of their contact with each other (Berry, 2015). This process of acculturation occurs at the group level and at the

individual level. Changes at the group level involves social and institutional structures and cultural practices. At the individual level, a person goes through psychological changes, which occur over time (Berry, 2015). Although acculturation occurs with both cultures, this dissertation focuses only on the influence of Hmong elders' acculturation at the individual level. Furthermore, Berry's acculturation typology with four strategies (assimilation, integration, separation and marginalization) (2015) proposed and defined in Chapter 1 will be used as a guide for this study.

Lee and Green (2010) conducted a study with 110 Hmong adults in Wisconsin to study their acculturation processes using the East Asian Acculturation Measure tool (Barry, 2001). They found that Hmong ranked highest in integration, followed by separation, assimilation, and then marginalization, respectively. The findings from Lee and Green's study suggest the importance of examining acculturation's influence on Hmong elders' care preferences because the researchers found that the current ages of the participants were correlated with separation and assimilation. The participants' ages had a significant positive correlation with separation, such that the older the participant, the more likely they were to be separated. With regard to assimilation, a negative correlation was found with age such that the older the participant the less likely they were to be assimilated and the younger they were the more likely they were to be assimilated. No correlation was found between age and integration or age and marginalization.

The correlations between age of participants when they arrived in the United States and their current assimilation practice; however, differed from that of their current age. Age of arrival was significant and negatively correlated with integration and assimilation. In other words, the younger the participants were when they came to the United States, the more likely they were to have integrated or assimilated compared with older participants. On the other hand, the age of

participants coming to the United States was significant and positively correlated with separation and marginalization. The older the participants were when they arrived, the more likely they were to have practiced separation and marginalization than those who arrived at a younger age.

The researchers found different results for integrated and separated Hmong. The most integrated Hmong were those who came to the United States at a younger age, lived in the United States for longer periods of time, had higher educational levels, and were able to speak, read, and write well in English. On the contrary, the participants who were the most separated were those who arrived in the United States at an older age and were not able to read, write, or speak well in English (Lee & Green, 2010).

The findings from Lee and Green's study are important to consider when attempting to understand Hmong elders' EOL care preferences. The consideration of acculturation strategies is important because there may be variations among elders' acculturation strategies and these strategies may influence the care preferences they would like to receive during their dying process. Additionally, prior studies also revealed evidence suggesting that differing strategies of acculturation existed between children and elders (Rick & Forward, 1992; Tatman, 2001). Children tend to demonstrate more assimilation (Rick & Forward, 1992) while most elders tend to hold onto their traditional practices (separation), especially with regard to healthcare (Lor, 2017). This knowledge is important to consider in trying to understand how the process of acculturation may impact the elders' care preferences.

Intercultural Adaptation

Research studies provide evidence of the intercultural adaptations that Hmong have made since arriving in the United States over 40 years ago. Two intercultural adaptations in particular relate to the EOL care preferences of Hmong elders: employment and gender roles changing as a

result of the U.S.' economy. These adaptations have led to some changes in the type of care for Hmong elders (Gerdner et al., 2008) and at EOL (Culhane-Pera, 2003b).

Intercultural adaptation refers to the psychological well-being and sociocultural management that individuals possess, as a result of their acculturation (Searle & Ward, 1990; Ward, 2001). Psychological adaptation is defined as the satisfaction and overall emotional as well as psychological well-being of an individual. Sociocultural adaptation refers to the behavior and sociocultural skills that individuals gain to live effectively in their new environment. Although psychological and sociocultural adaptations are conceptually related, they are two distinct categories because they are predicted by different variables and occur in different patterns over time (Ward, 2001). Psychological adaptations are predicted by life changes, personality, and social support factors (Searle & Ward, 1990), and these psychological adaptations will vary over time (Ward, 2001). Sociocultural adaptations are predicted by the quality of contacts that people have with others in the host society (Ward & Kennedy, 1993), cultural distance (Searle & Ward, 1990), length of time living in the host country (Ward & Kennedy, 1996b).

Prior to their arrival in the United States, Hmong elders lived a lifestyle that supported the tradition of sons and daughters-in-law as caregivers. In their home countries, Hmong families lived with or near each other and worked on one farm together (Gerdner et al., 2008; Rasmussen et al., 2003) rendering employment outside of the home unnecessary. This lifestyle made it possible for Hmong elders to live with a son and his wife, who would provide the necessary care to them as their health failed (Culhane-Pera, 2003b; Gerdner et al., 2008). When the Hmong arrived in the United States, however, their lifestyles changed. They found that their traditional farming style was not the norm (Chan, 1993) and, as a result, many Hmong adopted the non-

farming lifestyle and resigned themselves to employment outside of the home (Lee, 2005). Adapting to the change in lifestyle led to Hmong families shifting from acting as a unit and having "one goal" to acting as individual members operating on "different schedules" (Gerdner et al., 2008, p.122). One result of this adaptation has been that many sons and daughters-in-law no longer have the flexibility to provide care to their elders at home (Culhane-Pera, 2003b; Gerdner et al., 2008) and these elders may find themselves using EOL care services from the Western healthcare system.

Based on Ward and colleagues' intercultural adaptation definition, Hmong adult children have adapted sociocultural skills by way of being employed outside of the home in order for them to live effectively in the United States. The effect of these adult children's adaptations on their elders' care preferences during the dying process, however, is relatively unknown. As a result, examining how elders' and their children's acculturation strategies and adaptations influence Hmong elders' care preferences is pertinent.

In addition to the consideration of employment adaptations due to the U.S.' economy, it is necessary to give attention to the changes in gender roles regarding the traditional EOL care for Hmong elders. Gerdner et al. (2008) found that Hmong women, who are the primary caregivers to their in-laws during illnesses or old age, struggle with this responsibility as well as the need for them to be employed outside of the home. The female caregivers shared that because of the traditional practice of the daughters-in-law being the caregiver for their husband's aging parents, they live in daily conflict with this role competing with their other roles as mother, wife, and career professional working outside of the home. Prior research studies found gender differences between male and female caregiver roles when providing EOL care to a terminally ill loved one (Culhane-Pera, 2003a; Her-Xiong & Schroepfer, 2018), which could suggest

implications for elders' care preferences during their dying processes. In a case study about a Hmong elder who had gall bladder cancer and was using hospice care services, the male leaders of the family made the decisions for the elder and attended meetings with the healthcare professionals (Culhane-Pera, 2003a). Her-Xiong and Schroepfer also found gender differences in terms of what Hmong elders believed to be caregiver responsibilities. Respondents shared that when an elder is terminally ill, family and relatives help take care of the elder. Women would be responsible for the domestic duties such as cooking and cleaning, while the men would be responsible for decision-making (Her-Xiong & Schroepfer, 2018). Despite these findings about gender roles, other researchers have also found that Hmong women are becoming more active in decision-making, especially as it relates to their own health (Culhane-Pera & Xiong, 2003). Clearly, more research is needed to understand how Hmong elders view gender roles regarding their preferences during the dying process.

Conclusion

Although the findings in this literature review provide some understanding of Hmong EOL beliefs and rituals, no studies could be located that focused on Hmong elders' EOL care preferences that they believe would result in a quality dying process. Based on the literature, it was important that the role of acculturation, adaptation, and religion and spiritual beliefs be included in exploring Hmong elders' care preferences; therefore, this study aimed to explore the following research questions:

R1: What are Hmong elders' preferences for physical, psychosocial, and cultural care during their dying process?

R2: What are the differences and similarities of Hmong elders' care preferences for the dying process based on their acculturation strategy?

R3: Have Hmong elders made adaptations in their EOL care preferences and if so, what adaptations have they made?

R4: What role, if any, do adaptations made by Hmong elders' preferred caregivers play in the elders' care preferences with regard to their dying process?

R5: What role, if any, do Hmong elders' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences for their dying process?

CHAPTER 3: THEORETICAL FRAMEWORK

Studies on Hmong EOL care preferences have remained atheoretical except for one conducted by Lor (2017). In her study on the Hmong community's perceptions of mainstream EOL care services, Lor (2017) employed the Bowen Family Systems Theory (Chambers, 2009) and the Strengths Based Approach (Saint-Jacques et al., 2009) to explore the Hmong community's relationship with the geriatric health care system and how to address this conflict when facing difficult life decisions. Lor proposed that the Bowen Family Systems Theory could be used to understand dynamics within Hmong families with regard to EOL care services because of its focus on relationships and maintenance of an emotional equilibrium within a family context. The Bowen Family Systems Theory (Bowen, 1978; Crossno, 2011) views the family as the core of all relationships, emotions, thoughts, feelings, and proposes that the relationships family members have with each other result in interdependent connections such that a behavior change in one member impacts other family members (Bowen, 1978; Crossno, 2011). This concept is consistent with Hmong cultural beliefs and practices of family as the foundation. The theory guided how the study was designed to garner an understanding of how the Hmong community can be engaged in having conversations about using mainstream EOL care services. Lor's use of the Strengths Based Approach offered identification of factors that would promote EOL conversations for Hmong. The Strengths Based Approach places an emphasis on an individual's characteristics, environment, and potential to engage in life changes (Saint-Jacques et al., 2009). This theory asserts individuals as experts of their lives and interventions should

incorporate resources available in their environments (Arnold et al., 2007). This approach provided guidance to look at the influence of individual, culture, community, and provider to recognize attributes of the Hmong that could be supportive in promoting engagement of EOL services for Hmong.

Although the Family Systems Theory (Bowen, 1978; Brown, 1999) and Strengths Based Approach (Saint-Jacques et al., 2009; Arnold et al., 2007) offer guidance to understanding the Hmong community's relationship with the geriatric healthcare system in the United States and how to engage the community in having EOL care conversations by identifying factors that would promote Hmong's engagement of EOL care services, these theories do not address the role of acculturation (assimilation, integration, separation, marginalization), timing of events, and impact of historical events have on individuals' lives. It was important to use a theory that considers these factors because they could impact Hmong elders' care preferences for the dying process. Acculturation could impact Hmong elders' care preferences because of their interactions with the dominant culture in the United States. Timing of events is important to consider because Hmong elders' experiences of life events may also influence how they acculturate and prefer care. The impact of historical events on people's lives is pertinent to this study because it provides understanding to Hmong elders' immigration to the United States.

Life Course Theory

A theory that does provide consideration to the impact of acculturation, the timing of events, and historical influences on current events is the Life Course Theory, also known as the Life Course Perspective (Elder, 1985; Elder, 1998; Elder, et al., 2003). The theory focuses on human development within the individual's ecological context, with an emphasis on timing, social influences, life choices, and historical events (Elder & Rockwell, 1979; Elder et al., 2003;

Giele & Elder, 1998; Elder & Giele, 2009). This theory offers a holistic perspective to understanding human development and acknowledges the heterogeneity within people's lives, which is important for studying phenomena related to Hmong elders. In relation to this study, the Life Course Theory offers guidance to understanding the impact of the Secret War, migration, acculturation, and adaptations vis-à-vis Hmong elders.

Theory Development

The development of the Life Course Theory began with Elder's articulation of the theory in his book, *Children of the Great Depression*, Elder articulated the Life Course Theory (1974), wherein he traced the life patterns of children and their families' adaptations during the Great Depression. Elder also drew from previous work by scholars, especially those of Thomas and Znaniecki and identified four factors that influenced individuals' lives: *historical and geographical location, social connections with others, personal control, and variations in timing* (Giele & Elder, 1998). As Elder continued his scholarship with colleagues on the life course theory, the principles became more refined. In combining his four elements with the work of Giele, who studied life course changes of women in *different contexts*, the linked frameworks from Elder and Giele provided guidance to studying the intersection of the individuals and their environment. In doing so, the life course paradigm emerged consisting of the following four principles: historical time and place, linked lives, human agency, and timing of lives (see Figure 1 for a diagram of the Life Course Paradigm) (Elder & Giele, 2009). As the theory evolved, additional principles such as that of *human development as a constant process* (Elder et al., 2003) and *diversity in life course trajectories* (Elder, 1998; Shanahan, 2000) were added, as well as the concepts of trajectory, transition, and turning point. For the current study, it is important to delve deeper into the theory and how it is appropriate for gaining an understanding of the

physical, psychosocial and cultural preferences Hmong elders deem as essential to a quality dying process, as well as how acculturation, adaptation, religion and spiritual beliefs may influence these preferences.

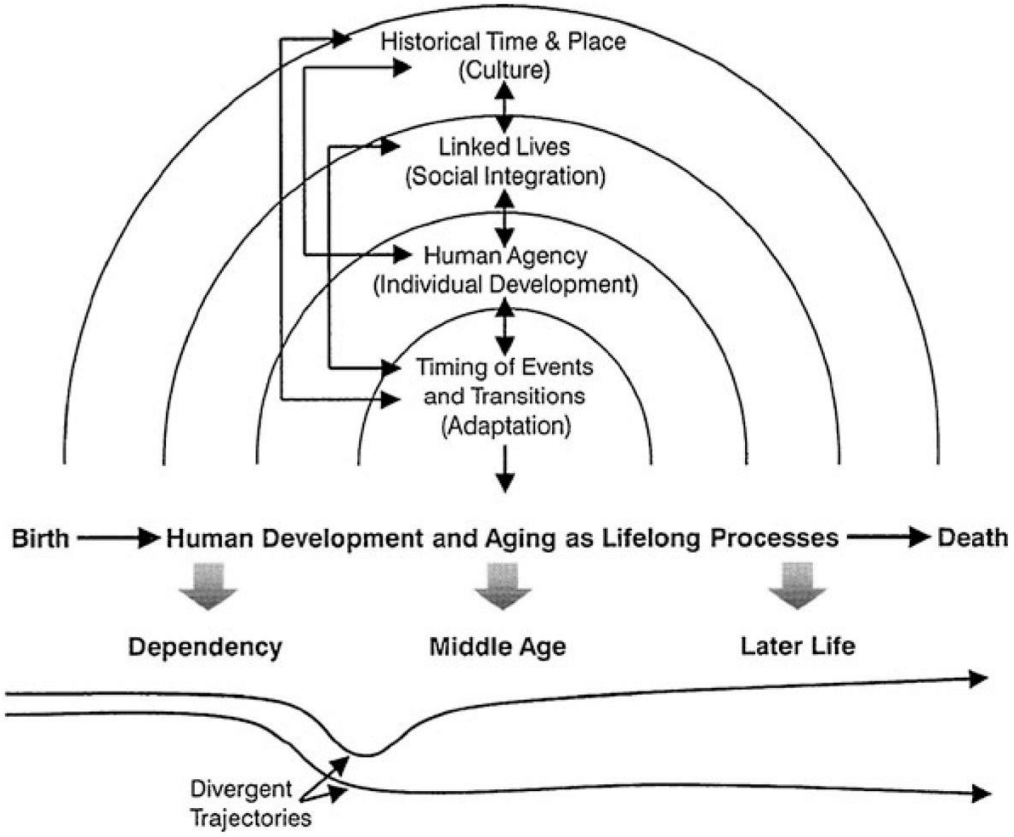

Figure 1. Elements of the life course paradigm, which is the convergence of Elder's and Giele's work on life course. This figure shows an example of how Elder's framework was combined with Giele's to expand the life course paradigm (Elder and Giele, 2009).

Life Course Paradigm

The Life Course Theory is a paradigm for studying the intersection of people's lives, their social contexts and the changes in those contexts over time that relate to their lives. Giele & Elder (1998) define the life course as a "sequence of socially defined events and roles that the individual enacts over time" (p. 22) and the effects of these events on their development. The

Life Course Theory has been used in an array of studies on phenomena such as preventive health (Worabo, 2017), caregiving to terminally ill loved ones (Francis et al., 2016; LaValley & Gage-Bouchared, 2018) and immigration (Treas & Guernskaya, 2016). The Theory consists of principles and concepts to understand human development, historical events, timing, and social contexts. These principles and concepts can be used as a framework in providing guidance for researchers in the "formulation of empirical questions, conceptual development, and research design" (Elder et al., 2003, p.10).

Life Course Theory Framework and Application

Principles

The principles in the Life Course Theory are used for this study include: *principle of human development and aging as lifelong processes*; *principle of human agency; principle of time and place; principle of timing in lives; principle of linked lives;* and *diversity of life course trajectories.* These principles shape the life course and human development and are useful for tracing and understanding the intersection of the individuals and the influence of their environment, as well as the changes that occur in those contexts. In relation to this study, the principles supported the importance of exploring the influence of acculturation, adaptations, historical events, and other contextual influences on Hmong elders' care preferences for the dying process.

Principle of Human Development and Aging as Lifelong Processes. This principle states that because humans develop biologically, psychologically, and socially throughout their life, an individual's behaviors must be analyzed via a long-term perspective and not just at one specific point in life (Elder et al., 2003). Events that occur early in people's lives affect their reactions to experiences that occur later in life (Elder at al., 2003); therefore patterns and

behaviors in later years of life must be examined with knowledge of events that occurred earlier in the life course (Elder, 1994).

Although this study was conducted at one point in a Hmong elder's life, this principle supported the importance of exploring the elder's experiences in their home country prior to immigrating to the United States, their experiences living in the United States, and how these experiences impact their care preferences for the dying process. As human beings are constantly evolving (Elder et al. 2003), this principle also supported asking questions related to the acculturation strategy the Hmong elders used and how this strategy and the resulting adaptations influence their EOL preferences.

Principle of Human Agency. This principle states that human beings create their own life course through the choices they make and the actions they take within the opportunities and constraints that occur in their lives (Elder, 1998; Elder et al., 2003). Although an individual's decisions are subjected to the limitations and opportunities available within their environment, they have autonomy in the choices they make, and these choices have important implications for the future.

This principle provides support for asking Hmong elders about their acculturation strategies and adaptations after relocating to the United States and how limitations and opportunities in their new environment may have impacted those choices. These elders made the decision to immigrate to the United States and because of their human agency it is likely that not all will have acculturated and adapted in the same way. According to the principle, the choices they made may have implications for their EOL care preferences and, hence, were important to explore in this study.

Principle of Time and Place. The historical times and places individuals experience in their lifetime shape their life course (Elder et al., 2003). An individual's experiences with historical events may differ in meaning based on where the individual was located during the event. Additionally, the effects of historical events on human beings create a cohort effect.

In regard to Hmong elders, their experiences during the Secret War, possible time spent in refugee camps, and immigration to the United States, may result in a cohort effect. This cohort effect, however, would likely differ for some elders, who due to their age during the war, might have experienced the above events at different times and locations. For example, during the Secret War, some elders were heavily involved with the CIA as soldiers, while others were not and were helping to tend to their families at home. This principle supports the consideration that Hmong elders, who were at different places during the Secret War, will have different experiences related to the war. These different experiences may have influenced their acculturation strategies and adaptations, which in turn may have impacted their care preferences for the dying process. As a result, this principle provided support for asking questions related to Hmong elders' immigration to the United States, and how their acculturation and resulting adaptations have influenced their EOL care preferences.

Principle of Timing in Lives. The principle of timing refers to how an individual experiences events in their life may differ based on when they occur in the life course (Elder et al., 2003). In other words, the same events can affect individuals differently based on when they occur in an individual's life. If these events are experienced out of the expected social order, the individual will experience physical and social consequences different from those who experienced these events in the expected order (Black et al., 2009).

In this study, the principle of timing in life supports the exploration of how they acculturate and the adaptations they made could have been influenced by when during their life course they immigrated to the United States. For example, some elders might have immigrated when they were young adults and may have chosen to assimilate, while other elders immigrated later in life and may be experiencing separation. According to this principle, the possibility exists that the result of experiencing different acculturation strategies and adaptations may influence Hmong elders' care preferences for their dying process.

This principle also supports the consideration that immigrating to the United States was likely a different experience for Hmong elders and their children and could have influenced their acculturation and adaptation choices. In turn, the children's acculturation and adaptations choices could also influence Hmong elders' care preferences for their dying process. The impact of children's acculturation and adaptations on elders' preferences is explained further by the next principle: *linked lives*.

Principle of Linked Lives. The principle of linked lives states that individuals' lives are inter-dependent (Elder et al., 2003). The term linked lives refers to the integration of relationships, which includes not only family members but friends, neighbors, and others such as colleagues (Marshall & Mueller, 2003). These social links not only influence a human being's interpretation of life events, but also the cultivation of new links can lead to behavior change in their life and in the lives of those socially linked to the individual (Elder et al., 2003).

This principle provided support for the consideration of how Hmong elders and their children's lives are inter-dependent. For example, evidence exists that the traditional practice of Hmong elders preferring their sons and daughters-in-law for caregiving at old age and EOL may be impacted by the lifestyle in the United States, which has led to many Hmong adult children

and their partners/spouses having to seek full-time employment (Gerdner et al., 2008). This adaptation of Hmong adult children being employed full-time could influence a Hmong elder's EOL care preferences because of their inter-dependent lives. It is important, therefore, that this study sought to explore how Hmong elders' children's acculturation strategies and resulting intercultural adaptations may have influenced elders' care preferences for the dying process.

Principle of Diversity in Life Course Trajectories. This principle brings attention to the diversity and different experiences in people's life patterns, especially within cohorts and a global context (Hutchison, 2010). Individuals' life course trajectories vary by factors such as class, location, gender, sexual orientation, legal and social statuses, and the type of nation they live in (developed vs. developing) despite their being in the same birth cohorts (2010). Other factors that may influence trajectories include religion and spirituality. This principle considers people's different experiences of similar life course trajectories such as work, education, and illness. For example, research has found that men and women's career trajectories may differ based on historical and social influences such that despite most women being employed outside of the home, their career trajectories tend to be interwoven with the family domain, while men's career trajectories tend to be rooted only in employment outside of the home (Setftersen & Lovegreen, 1998). Similarly, people's religion, spiritual beliefs, and spiritual practices also influence life course trajectories because it guides their decisions, especially with regard to EOL care. For Animist Hmong, their religion, spirituality, and healthcare beliefs are interwoven. Hmong Animists' (religious) beliefs regarding the cause of illness is that of soul loss (spirituality) and doing shaman ritual is one healing method to cure the illness (Her-Xiong & Schroepfer, 2018). Hmong Christians, however, believe in the importance of prayers as a healing practice and the presence of God's guidance (2018). The diversity of and interlink between these

entities make it necessary to consider them when attempting to understand Hmong care preferences for the dying process.

This principle provided support for asking questions about Hmong elders' gender, religion, spiritual beliefs and practices, acculturation strategy, and resulting adaptations. Hmong elders' gender and differing religions and spirituality may influence their EOL care preferences. Similarly, this principle also considers the different acculturation strategies that elders use and their adaptations as they relate to their care preferences. Overall, this principle served as guidance to asking questions related to all of these factors in order to understand the diversity of Hmong elders' care preferences for their dying process.

Concepts

In addition to the principles proposed by Elder and colleagues, they also present three concepts to understanding events that occur in people's lives and are integral to their life courses (2003). These concepts of the Life Course Theory include transitions, trajectories, and turning point.

Transitions. Transitions are the changes in statuses or roles that promote behavioral change and represent a departure from one's previous statuses and roles (Elder et al., 2003). Many transitions are related to the concept of family in that they often include family members' exits or entrances (Hutchison, 2010). Examples of such transitions include leaving parents' home, becoming a parent, or marriage. The timing of a transition in one's life course impacts the meaning of the transition (Elder et al., 2015). Transitions early in life may have lifelong effects by influencing how events, experiences, and other transitions transpire later in life. The time between the occurrence of transitions is known as duration and the longer the duration, the more

stable the behavior is related to the transition because of one's obligations and vested interests in that certain transition (Elder et al., 2003).

In this study, a transition explored was the experiences of Hmong elders and their adult children acculturating to the United States. How they transition, however, is based on their acculturation strategy and the resulting adaptations, both of which may influence the elders' EOL care preferences. The children's acculturation and resulting adaptations may impact their family structure in that they may have to leave home and live in separate dwellings from their elders because of the relocation of their jobs. Therefore, it was important to capture such information when seeking to answer how a Hmong elder's acculturation strategy may have influenced their EOL preferences. Additionally, it was also necessary to explore whether these elders had made intercultural adaptations in their care preferences based on their acculturation strategy, as well as those of their adult children's.

Trajectories. Trajectories are the sequences of roles and experiences in one's life course and are made up of multiple transitions (Elder et al., 2003). For example, transitions such as leaving parents' home, entering college, graduating from college, and starting a new job can make up one's career trajectory. Trajectories are the long-term views of patterns and changes in one's life that persist over time and are interconnected with other people's lives and trajectories (Elder et al., 2003). For the most part, people follow patterns that are deemed culturally normal regarding the sequencing of roles, experiences, and transitions. These patterns are known as social pathways that are often gender-specific and shaped by cultural and institutional regulations (Elder et al., 2003). Although trajectories are not necessarily straight paths, they make up the pathways human beings follow (Hutchison, 2010). Elder et al. (2003) argued that individuals

create their own trajectories based on cultural and institutional norms and these trajectories are subject to change based on opportunities and limitations within the individual's environment.

In this study, the trajectory explored was the course of the dying process for Hmong elders. In the mainstream culture, the dying process involves the medical model, which may include the use of hospitals and services such as hospice care. For the Hmong, their dying trajectory would normally involve their traditional healthcare system; however, having immigrated to the United States, this is subject to change because the practice in the United States may limit the Hmong's ability to practice the traditions in their healthcare system. Therefore, as Elder et al. (2003) noted, these Hmong elders may also create their own dying trajectories based on the healthcare system and caregiving services available in their contexts. This concept takes into consideration that Hmong elders may prefer a dying process trajectory based on their cultural norms, acculturation strategy and resulting intercultural adaptations. Their dying process trajectory may also be impacted by their adult children's adaptations.

Turning point. A turning point is an abrupt and substantial change in the direction of an individual's life course (Elder et al., 2003). Examples of turning points include an adult returning to school (Elder et al., 2003) or becoming a mother to a medically fragile pre-term baby (Black et al., 2009).

The turning point in this study is the immigration of Hmong elders to the United States. This immigration was a major turning point because it subsequently impacted the lifestyles of Hmong in terms of families' living arrangements and caregiving for elders (Gerdner et al., 2008). The proposed study sought to explore the impact that this turning point may have had on the dying trajectory.

Conclusion

The Life Course Theory served as an appropriate framework to guide the study of Hmong elders' care preferences for their dying process. The application of the theory assisted in exploring Hmong elders' EOL preferences and how they may have been influenced by acculturation, adaptation, religion and spiritual beliefs. Additionally, the theory framed the exploration of prior events in the elders' lives that may have contributed to their current EOL care preferences. It should be noted, however, that no testing of the theory nor acculturation strategies were conducted in this study due to the small sample size and the sensitivity of placing people into categorizations that do not reflect the true diversity of their experiences.

CHAPTER 4: METHODS

This exploratory and descriptive study was conducted to garner an understanding of Hmong elders' care preferences for the dying process. Over a five-month period, I conducted 30 face-to-face semi-structured interviews with Hmong elder participants, who were not terminally ill. The participants were recruited through organizations and agencies that serve the Hmong community in Wisconsin. Due to confidentiality purposes, the participating organizations and agencies will not be named. The interview consisted of qualitative and quantitative questions, and all 30 interviews were included in the final analysis. The analysis consisted of conventional and directed content qualitative analytical techniques and descriptive statistics for the quantitative data. This study received IRB approval through the UW-Madison Social and Behavioral Science Institutional Review Board. In this chapter, the sampling criteria, sampling procedure, data collection, interview guide development, measures, data analysis, and rigor are discussed.

Sampling Criteria

Respondents were eligible for this study if they were 60 years or older, born in Southeast Asia and immigrated to the United States, spoke Hmong and/or English, and had at least one adult child living in the United States, who may or may not have been born an American citizen. In order to explore participants' acculturation strategies and how they related to their end-of-life care preferences, the sample was limited to those who were born oversees and now reside in the United States. Verbal communication was limited to Hmong and/or English as I am fluent in both and other languages would be beyond my capacity. The requirement that respondents have at least one child living in the United States was key to the study because research shows that sons and daughters-in-law are the preferred caregivers to Hmong elders, and that elders also prefer to live with them (Gerdner et al., 2008).

Thirty one-time face-to-face interviews were conducted with Hmong elder participants residing in Wisconsin. It was challenging to recruit Hmong elders because they are not familiar with research and may be less inclined to participate in a research interview because of trust issues, not understanding the purpose of research (Lor & Bowers, 2018), or the taboo placed by the Hmong culture on talking directly about death and dying (Vawter & Babbitt, 1997). I am a member of the Hmong community, who immigrated to the United States at the age of five, speaks Hmong fluently and knows the Hmong cultural etiquette when it comes to talking about sensitive topics such as death and dying. Lor and Bowers (2018) found that these characteristics of the interviewer were important in building trust with Hmong elders and motivating them to be more interested in participating in a research study.

Sampling Procedure

The sampling procedures used for this study were purposive and snowball. Purposive sampling is a method of selecting participants based on their ability to provide needed information for the study (Padgett, 2016). Snowball sampling is a process that involves recruiting a member of a population and asking that member to refer the researcher to other individuals from that population (Padgett, 2011). Snowball sampling is a method that has been successfully used in prior studies with the Hmong community (Yang & Solheim, 2007; Lor, et al., 2013; Lor & Bowers, 2014) because it is respectful of the potential participants (Lor & Bowers, 2014) and engenders their trust (Lor et al., 2013). Trust is more likely to be created between the researcher and the potential participant when the referral source has a relationship with the potential participant and introduces them to the researcher (Lor & Bowers, 2018).

Using the purposive sampling procedure, I sought assistance with recruitment from organizations and agencies located in Wisconsin and Minnesota, all of which provide services to Hmong elders. In total, letters were sent to three home care agencies in Wisconsin and five non-profit organizations in Wisconsin. Letters were also sent to five adult day centers in Minnesota. Out of these thirteen agencies, directors from two organizations in Wisconsin agreed to participate. No agency directors from Minnesota responded to my letters. I met with directors from the two agencies in Wisconsin to present my study, discuss the recruitment process, who in their agency would make referrals, and what would be required of these agency personnel regarding their participation. At the meeting, I provided the directors with folders containing two copies (one in English and one in Hmong) of the consent form (Appendix E), letter of introduction (Appendix C), and flyer (Appendix A) so that they would have the necessary documents for the referrals. I also provided additional folders containing two language versions

of the letter of introduction and flyer for agency personnel to give to potential participants. I obtained a letter of support from the agencies and included them in my University of Wisconsin-Madison-Madison IRB application.

When personnel from the participating organizations and day centers met with a Hmong elder who was eligible to participate in my study, they gave them a prepared folder. The letter of introduction thanked the elder for their interest, explained the study's purpose, risks and benefits, and provided information on who I am and my contact information. The person recruiting the elder provided them with these documents and offered to read them aloud beginning with the letter of introduction. After learning about the study and expressing interest in participating, the recruiter explained that they could refer them to me and I would contact them or they could contact me. If the elder preferred to contact me, they were told to do so by calling the phone number listed on the flyer. If the elder was interested in participating but preferred the person recruiting them to contact me, they would obtain the elder's verbal consent to provide me with their contact information including name and phone number so I could follow up and answer any questions. If after talking with me the elder still wanted to participate, I confirmed their willingness and voluntary decision to do so and scheduled a time for the interview, which was conducted in a location of their choosing.

In addition to agency personnel recruiting participants on an individual basis, I used a second purposive recruitment strategy found to be effective in recruiting Hmong elder participants (Lor & Bowers, 2018). I personally presented my study to groups of Hmong elders who participated in a community health fair organized by one of the agencies participating in my study. I asked interested elders to provide me with their contact information and then followed up with them.

The second recruitment method I used was snowball sampling. At the end of each interview, I asked the participant, if they knew other Hmong elders who met the criteria and would be interested in the study. If they did, I provided them with the appropriate language version of the letter of introduction and flyer containing my contact information and asked that they share it with potential participants. I also employed snowball sampling with family and community members who were not related to the participants. These family and community members were people whom I met in the community and asked if they would tell other Hmong elders about my study. These members were informed that they were not to screen the interested participant for eligibility; rather, they were to simply inform the interested elders of the study and to contact me for questions. The purpose of this method was to reach elders who may not have used agency services and would not have known about the study without their family or other community members informing them.

The combination of purposive and snowball sampling methods enabled me to recruit 30 Hmong elder participants throughout Wisconsin. Nine of the 30 participants (30%) were recruited via purposive sampling and all agreed to participate. A total of 27 (20 from community members and seven from interviewed participants) were recruited via snowball sampling; however, six recruited by interviewed participants either were not interested or could not be reached. The use of both sampling methods was valuable in effectively recruiting Hmong elder participants.

Data Collection

Thirty face-to-face interviews were conducted at a location chosen by the participant. Twenty-one (70%) interviews were completed at home, five (16%) at an agency, and four (13%) in a private space at a community event. Once the participant and I met, I asked if they preferred

the interview be conducted in Hmong and/or English. I then asked if they wanted me to read the consent form aloud or read it themselves. If after reading the consent form the older adult wanted to participate, I asked them to sign the form and gave them a copy to keep.

The participants were also informed of the option to have another elder or person in the room during the interview. Fifteen (50%) participants chose to have another person in the room: 10 (30%) chose their spouse, two (7%) an adult child, and three (10%) a friend.

There were several tasks that needed to be completed prior to starting the actual interview. After the consent form was signed by the elder and they had given permission to be recorded, I set up two recorders to audio-record the interview. The use of two recorders was to prevent the loss of data should one recorder malfunction during the interview. I offered the participant the option of using a pocket talker, a device that amplifies sounds and reduces background noise for individual with hearing deficits. All participants declined and did not appear to experience any difficulty hearing me during the interview. Before starting the interview, I reminded the participant to let me know if they became fatigued or uncomfortable and required a break. I also told them that they could end the interview at any time and that I would honor their wish to do so. All participants completed the interview without a break. The interview guide contained both quantitative and qualitative questions and was designed to be completed in 30 minutes. The participants completed the interview between 16 and 102 minutes with a mean of 40 minutes and a range of 86.

Interview Guide Development

The interview guide (see Appendix G) used in the face-to-face interviews was designed with several considerations. The Life Course Theory (Elder et al., 2003; Elder, 1998), Berry's acculturation typology (Berry, 1997; Berry, 2015; Sam & Berry, 2010) and Ward's intercultural

adaptation framework (Searle & Ward, 1990; Ward, 2001) framed the design of the questions. Additionally, knowledge gathered from the literature review, and feedback from Hmong studies scholars, elders, and community leaders were considered when creating the interview guide. The intention was to design a culturally sensitive interview guide for Hmong elder participants and to place them at ease.

Section One

Section One of the interview guide contained demographic questions and served two purposes: to ease participants into the interview process and provide information on their background. In this section, participants were asked their age (Q01), gender (Q02), marital status (Q03-Q3a), how they came to live in the United States, the year they arrived in the United States, and their country of birth (Q04-Q4b). Next, they were asked about speaking and writing in English (Q05-Q05a) and in Hmong (Q06-Q06a). If a participant was already speaking either of the languages, I would skip questions related to that language and ask about the other. For example, if a participant was already speaking Hmong, which was the case for all participants, I asked Q05, Q05a, *skipped* Q06, and asked Q06a. Several questions were then asked about the participant's education, such as the total number of years they attended school, the country in which they attended school, and how long they attended school in each country (Q07-Q07b1). Participants were next asked about their current employment status (Q08), and type of work they were doing (Q08a) if employed. If they were not working, they were asked the reason (08b). The next set of questions focused on their religious practices, such as what their current religious practices were and if they have always practiced that religion (09-09f). The last few questions in the demographic section were about the participants' children and members of their household. The questions included whether they had children and if so, how many (Q10-Q10a), whether

anyone lived with the participant and if so, who were those individuals (Q11-Q11a). The Principle of Linked Lives states that the lives of people who live in the same environment are inter-dependent and a change in one person's life can affect the lives of the others (Elder et al., 2003) thus information about their household was important to gather. While this principle would extend to beyond immediate families in the Hmong culture, this study's focus is on the immediate family members.

Section Two

This section focused on gaining knowledge of the acculturation strategy participants used after immigrating to the United States. Although an acculturation scale would have been preferred, after discussions with other researchers who have conducted studies with the Hmong community, it was decided that an acculturation scale would not be appropriate for use with Hmong elder participants. Scales are not culturally or linguistically appropriate to be used with Hmong elders. For example, response options for a Likert-scale tend to be confusing to the elders because there is no direct translation of the answer options such as "agree", "disagree", "yes", and "no". Also, when testing the scale with elders, they naturally answered the questions as if they were open-ended. Based on this feedback, I asked one open-ended question with prompts to inquire about the participants' acculturation strategies (Q12). The question, *"What is your life like as a Hmong elder living in the United States?*" was asked so that participants could talk about their lives in the United States and any acculturation or adaptations they may have made. Following this question, I asked six prompts if the participants did not cover the content in their answers to Q12. The prompts were about cultural traditions, spending time with Americans, language, support, socialization, and food.

Cultural Traditions. The first prompt was *"How important is it for you to keep practicing Hmong traditions?"* Although a majority of Hmong traditions include Animism practices, some traditions are not religious such as childrearing and caregiving. This question was kept broad so that participants could answer it in whichever way they felt comfortable. This question was considered because past researchers have found that immigrants adapt based on cultural practices from their home countries and those of the new society (Foner, 1997; Kwak & Berry, 2001). Previous researchers have also used cultural traditions to measure acculturation strategies (Kwak & Berry, 2001).

Spend Time with Americans. The second prompt was and open-ended question that asked participants *"How important is it for you to spend time with Americans?"* This question was adapted from the East Asian Acculturation Measure, which specifically asked about participants' attitudes toward socializing with Americans (Barry, 2001; Lee & Green, 2010). This question is different from the socialization prompt below because this one is specific towards one group of people in the United States while the prompt below is broad and asked to understand participants' general socialization behavior.

Language. The third prompt was *"What language do you usually speak?"* This question was asked despite the language that the participant was using for the interview. Speaking the host country's language is considered by researchers to be a key dimension of measuring acculturation because of its predictability in group membership (Anderson, 1993).

Support. The fourth prompt was *"Who do you usually go to for support?"* This question was asked so that I could understand better participants' acculturation to living in the US. Having a higher level of social support among friends and families has been found to lower depression

levels (Kim et al., 2012) and increase quality of life (Wong & Lu, 2017) among Asian immigrants who were highly acculturated compared to those who were not.

Socialization. The fifth prompt was *"Who do you usually spend your free time with?"* This question was asked so participants could talk about their socialization behavior. As acculturation is the process of social and communication responses to others in a host culture (Berry, 1997; Barry, 2001), it was important to understand how participants were generally socially interacting with people in the United States.

Food. The last prompt was *"Do you usually eat Hmong or American food?"* This question was asked because food acculturation has also been found to be a part of immigrants' acculturation processes in which they may adopt eating patterns or food choices from their new environment, preserve their traditional foods, or integrate their traditional foods with that of the host (Satia et al., 2001; Satia et al., 2000).

Question 12 and the six prompts about the participants' acculturation strategies were guided by two Life Course Theory principles (Elder et al., 2003; Elder, 1998) and prior acculturation research findings (Anderson et al., 1993; Berry, 1997; Kwak & Berry, 2001; Sam & Berry, 2010; Barry, 2001). The first is the Principle of Human Development as a Lifelong Process, which states that people continue to develop beyond adolescent years (Elder et al., 2003). For Hmong elders who have immigrated to the United States, this principle supports the inquiry into how these elders have changed and developed since immigrating to the United States. The second principle is the Principle of Human Agency, which states that people create their own life course through their choices and actions base on the limitations and opportunities within their environments (Elder et al., 2003). This Principle suggests that these participants have the agency to acculturate based on the supportiveness of their surroundings. These principles

lead to exploring how the participants have changed and the acculturation strategies they have used to adjust to life in the United States.

Section Three

Section Three contains sensitive questions related to the participant's care preferences during the dying process, any spiritual beliefs and rituals influencing their care preferences, and who are their preferred caregivers. This section begins with the phrase 'When you have an illness that cannot be cured' in order to avoid the risk of causing emotional harm to the participants by using the word 'die or dying'. The use of this phrase was suggested by Hmong elders who participated in a prior study on Hmong EOL beliefs and rituals (Her-Xiong & Schroepfer, 2018).

Caregiving Preferences. Several questions in Section Three sought to gather information about the participants' care preferences. This section began with an open-ended question asking the participants to talk about a time when they provided care to someone (Q13). This question was created to ease the participant into talking about caregiving in general prior to focusing on their own EOL care preferences and so responses to this question were not analyzed. The next question asked what the participant's care preferences would be if they were to have an illness that could not be cured (Q14). The open-ended question was written so as to not be leading and bias the participant's responses. I did, however, create four prompts to ask the participant, if they did not address particular content in their responses. The Principle of Diversity in the Life Course Trajectory, states that people's life course trajectories vary by factors such as class, location, gender, social statues, religion, spirituality, and culture despite being in the same cohort (Hutchison, 2010). This principle guided the prompts, which sought information on the types of care commonly practiced in the Hmong culture that the participant

would like to receive, and care related to spiritual beliefs and rituals. The question about who the participant would like to provide care for them was guided by the Principle of Linked Lives.

In addition to the diversity of life experiences and cultural practices, answers to Q14 provided insight into the trajectories of the participants' care preferences during the dying process. In this study, the course of their future dying process trajectory was explored because Hmong elders' dying trajectories may be subjected to influences from societal practices in the United States.

Adaptations. Guided by the Principle of Linked Lives (Elder, 1998; Elder et al., 2003), the next open-ended questions were asked to gain understanding of the impact participants' preferred caregiver's adaptations have had on their own care preferences. The first question asked was (Q15) *"You have talked about the types of care you would want to receive if you had an illness that could not be cured. Do you believe you will receive this care?"* Regardless of the participants' answers to this question, a follow up question asked them to explain the reason behind their answer (Q15a): "*Would you please say more about why you feel this way?"*. The next question (Q16) asked was *"You just told me that you would like _____ (fill in respondent's preferred caregiver) to provide the care to you. Do you think that _____ (participant's preferred caregiver(s)) will provide this care to you?"* Again, regardless of their answer to Q16, the following question was asked so that they could elaborate on their responses (Q16a) "*Would you please say more about why you feel this way?"* This question provided an opportunity for the participants to share their perspectives on their preferred caregivers' adaptations.

To better understand the impact of their preferred caregivers' adaptations on the participants' care preferences for the dying process, I included a question that asked if their

preferred caregivers were not available to provide the care, who would be their alternative preferred caregiver. Question (Q17) asked *"If your _____ (participant's preferred caregiver) could not provide the care for you, who else would you like to give you this care?"* This question was included because the participants' preferred caregivers may have made adaptations that resulted in their being unavailable to provide the care to the participants. This question was asked to gain a better understanding of the intercultural adaptations that participants made with regard to their caregivers. For example, Gerdner et al. (2008) found that it is a tradition for Hmong elders to be cared for by their sons and daughters-in-law but as these children become less available to provide the care for them, their grand-children and other relatives become the caregivers or Hmong elders use care facilities.

Lastly, the final question in this section was regarding whether and how the participants' care preferences for the *dying process* had changed since coming to the U.S (Q18) and sought to understand how these changes may have come about due to their acculturation strategies and any adaptations that resulted from acculturating. This question asked *"After having lived in the United States for a while, do you feel that the care you would have liked to receive when you lived in _____ (insert country) is different than the care you would want now?"* Following their response to this question, they were given an opportunity to elaborate on their reasons with the question "*Would you please say more about why you feel this way?"* This question was created with guidance by the Life Course Theory's Principle of Human Development and Aging as Lifelong Processes, Principle of Human Agency, Principle of Time and Place, and Principle of Timing in Lives (Elder, 1998; Elder et al., 2003). The Principle of Time and Place states that people's experiences with historical events may have different meanings for them based on where they were located during the event (Elder et al., 2003). For

Hmong elders, the Vietnam War, time spent in refugee camps, and immigration to the United States may have different meaning even though they all experienced the same events. The Principle of Timing in Lives refers to how people may experience life events differently based on when the events occurred in their life (Elder et al., 2003). For example, some elders immigrated to the United States when they were young adults while others immigrated as elders. With guidance from the four principles, this question and prompts sought to capture how participants' care preferences have changed since arriving in the United States.

Section Four

The "Final Thoughts" section of the interview guide contained two questions. The first was to ask participants if they had any questions or wanted to share any remaining thoughts. The second question asked if the participants knew anyone who may be interested in participating in the research study (i.e., snowball recruitment).

Section Five

Section Five contained post-interview questions for me as the interviewer to complete after I had left the interview. This section allowed me to collect information about the referring agency, referral source, and location of the interview.

Measures

The following demographic variables were measured quantitatively: age, gender, marital status, number of years lived in the United States, country of birth, speak in English, fluency of speaking in English, write in English, fluency of writing in English, speak in Hmong, write in Hmong, education, employment, religion, number of children, other individuals who live in same household as participant. For each variable, the corresponding interview guide section and question number are listed below.

Age

Age was measured as a continuous variable (Section 1, Q01). The age of the participants ranged from 60 to 89, with a mean of 69. The age distribution was skewed right (.92), which means the participants in this sample tended to be younger older adults.

Gender

Participant's gender (Section 1, Q02) was coded as a dummy variable: 0=female and 1=male. Of the 30 participants, 20 (66%) were females and 10 (33%) were males.

Marital Status

Marital status (Section 1, Q03) was coded as a categorical variable with 0=single/never married (N=0, 0%), 1=married (N=19, 63%), 2=separated (N=0, 0%), 3=divorced (N=2, 6%), and 4=widowed (N=9, 30%). Due to the zero cases for single/never married and separated categories, marital status was recoded to "married" and "not married" with 0=not married (N=11, 37%) and 1=married (N=19, 63%). If participants were married, they were asked if their spouse lived with them (Q03a), and answers were coded as a dummy variable 0=no and 1=yes. Answers to the recoded variable and Q3a were combined and recoded into a new variable: 0=single/never married (N=0, 0%), 1=married, living with spouse (N=19, 63%), 2=married, not living with spouse (N=0, 0%), 3=living with partner (N=0, 0%), 4=separated/divorced (N=2, 6%), and 5=widowed (N=9, 30%). Because of the cases in each category, the variable was recoded to 0=not married/not living with spouse/separated/divorced/widowed (N=11, 36%), 1=married and living with spouse (N=19, 63%).

Number of Years Lived in the United States

The year that the participants immigrated to the United States (Section 1, Q04a) was subtracted by the year of the interview to calculate the number of years the participant had been

living in the United States. This variable was measured as continuous and responses ranged from 5 to 43, with an average of 35 years.

Country of Birth

Location of birth (Section 1, Q04b) was coded as a categorical variable with 1=Laos (N=29, 97%) and 2=Vietnam (N=1, 3%).

Speak in English

This variable (Section 1, Q05) was coded as a dichotomous variable: 0=No (N=17, 57%) and 1=Yes (N=13, 43%).

Speak in English Fluency

This variable was not originally created because when asked whether participants spoke in English, I did not ask them for their level of fluency. The 17 participants who responded they spoke English, however, voluntarily shared their fluency and used one of three words to describe it. As a result, this variable was measured categorically using their word choice with 1=a bit (N=7, 23%), 2=some (N=3, 10%), 3=a lot/comfortably (N=3, 10%), and 98=NA (N=17, 57%). The value 98 was assigned to those who did not speak in English.

Write in English

Regardless of participants' response to whether they could speak in English, they were asked Q05a (in Section 1) "*Do you write in English?"* Responses were dichotomously coded as 0=No (20, 67%), and 1=Yes (N=10, 33%).

Write in English Fluency

Again, when asked whether they could write in English, the participants willingly shared their fluency level. This variable was coded as categorical with 1=a bit (N=7, 23%), 2=some

(N=0), 3=a lot/comfortably (N=3, 10%), and 98=NA (N=20, 67%). Again, the 98 was assigned to participants who shared that they could not write in English.

Speak in Hmong

This variable (Section 1, Q06) was measured dichotomously as 0=No and 1=Yes. All participants reported speaking Hmong (N=30, 100%).

Write in Hmong

This variable (Section 01, 06a) was measured dichotomously as 0=No (N=16, 53%) and 1=Yes (N=14, 47%). Although all participants spoke the Hmong language, slightly less than half could write it, which is due to the written Hmong language being only in existence since the 1950's (Timm, 1994). Given that the Hmong culture has been traditionally oral, many elders either did not have the opportunity to learn the written language until they were older or did not learn it at all.

Education

Number of years of education (Section 1, Q07) was measured as a continuous variable based on the number of total years of schooling that the participant completed both in their home country and the US. This variable ranged from 0 to 20 with four being the average number of years of schooling completed. It is worth noting that 10 participants reported not having attended school in their lifetime.

Education Outside of the United States

The 20 participants who reported attending school were asked if they had done so outside of the United States (Section 1, Q7a). This variable was measured dichotomously with 0=No (N=6, 20%), 1=Yes (N=14, 47%), and 98=NA (N=10, 33%).

Country of Education Overseas

For the 14 participants who did attend school overseas, they were asked to provide the country's name (Section 1, Q07a1). This categorical variable was measured as 1=Laos (N=9, 30%), 1=Vietnam (N=1, 3%), 3=Thailand (N=2, 7%), 4=France (N=2, 7%), and 98=NA (N=16, 53%). Sixteen participants were NA because 10 reported not attending school at all and six reported not having attended school overseas.

Number of Years of Education Overseas

The number of years the 14 participants attended school overseas (Section 1, Q07a2) was measured as a continuous variable with responses ranging from .5 to 7 with a mean of 3.6 years.

Education in the United States

The 20 participants who reported attending school were asked if they had done so in the United States (Section 1, Q07b). This variable was measured dichotomously with 0=No (N=2, 7%), 1 = Yes (N=18, 60%), and 98=NA (N=10, 33%).

Number of Years of School in the United States

The 18 participants who reported having attended school in the United States were asked how many years they had done so (Section 1, Q07b). The question was coded as a continuous variable and responses ranged from 1 to 14 years with a mean of 4 years. Twelve participants were not included in this variable because they either did not attend school at all or attended school only overseas.

Education Location Overseas vs. United States

For the 20 participants who attended school either in the United States, outside of the United States or in both locations, a new variable was created based on the information ascertained in the two education location questions (Section 1, Q7a & Q7b). This categorical

variable was coded as follows: 1=overseas only (N=2, 6%), 2=United States only (N=6, 20%), 3=both overseas and United States (N=12, 40%), and 98=NA (N=10, 33%).

Employment

Participants were asked if they were currently employed (Section 1, Q08). Responses were coded into a dichotomous variable: 0=No (25, 83%) and 1=Yes (N=5, 17%).

Type of Work

The five participants who reported being currently employed were asked a follow-up question (Section 1, Q08a) about the type of work that they were doing. Participants' types of employment were measured categorically with 1=kitchen staff (N=1, 3%), 2=interpreter (N=1, 3%), 3=entrepreneur (N=1, 3%), 4=manufacturing (N=1, 3%), 5=bilingual assistant (N=1, 3%), and 98=NA (N=25, 83%).

Reason for Not Working

Twenty-five of the 30 participants reported they were not currently employed and were asked (Section 1, Q08b) the reason. Responses were measured as a categorical variable and coded as 1=laid off (N=1, 3.3%), 2=disability (N=10, 33.3%), 3=retired (N=14, 46.7%), and 98=NA (N=5, 16.7%).

Religion

Religion (Section 1, Q09) was measured as a categorical variable with 0=do not practice any religion (N=1, 3.3%), 1=Christianity (N=15, 50%), 2=Animism (N=14, 46.7%), 3=Christianity & Animism (N=0).

Have Always Practiced Religion

The 29 participants who reported they currently practice a religion were asked "*Have you always practiced _____ (insert answer from Q09)"* (Section 1, Q09a). Their responses were coded dichotomously as 0=No (N=13, 43.3%), 1=Yes (N=16, 53.3%), and 98=NA (N=1, 3.3%).

Religion Prior to Current One

The 13 participants who reported that they have not always practiced their current religion were asked what religion they practiced before their current one (Section 1, Q09b). This variable was measured categorically as 0=None (N=0), 1=Christianity (N=1, 3%), 2=Animism (N=12, 40%), 3=Christianity & Animism (N=0), 98=NA (N=17, 57%).

Country Living while Practicing Prior Religion

The 13 participants who practiced a different religion prior to their current one were asked which country they were living in when they practiced that previous religion (Section 1, Q09c). This variable was coded categorically with 1=Laos (N=2, 7%), 2=Vietnam (N=0), 3=Thailand (N=0), 4=United States (N=3, 10%), 5=Thailand & Laos (N=3, 30%), 6=Thailand, Laos, United States (N=4, 13%), 7=Laos, Thailand, France, United States (N=1, 3%), 98=NA (N=17, 57%).

Have Children

The participants were asked whether they had any children (Section 1, Q10). All of the participants reported having children.

Number of Children

All participants were asked the number of children they had (Section 1, Q10a). The variable was continuous with responses ranging from three children to 11 and a mean of 6.5.

Anyone Lives with Participant

All participants were asked if anyone else was currently living with them. Only one respondent reported living alone.

Other Individuals Who Live in Same Home as Participant

For the 29 participants who had other people living with them, I asked who they were. The responses varied, ranging from spouse only to spouse and children, to children and grand-children. Table 1 provides a list of people who participants reported as living with them.

Table 1

Who Lives With Participant

	N (%)
Spouse	4 (13.3)
Spouse, daughter(s)	1 (3.3)
Spouse, son(s)	5 (16.7)
Spouse, daughter(s), son(s)	3 (10.0)
Spouse, daughter, son, grand-children	2 (6.7)
Spouse, son(s), daughter(s)-in-law, grand-children	5 (16.7)
Daughter(s)	1 (3.3)
Son(s)	1 (3.3)
Daughter(s), son(s)	1 (3.3)
Daughter(s), son(s), daughter(s)-in-law	1 (3.3)
Daughter(s), son(s), grand-children	1 (3.3)
Son(s), daughter(s)-in-law, grand-children	3 (10.0)
Dad(s), son(s)	1 (3.3)
No one	1 (3.3)

Acculturation Strategy

After analyzing and assigning acculturation strategies to participants, this variable was created. This variable was measured categorically with 1 = separation (N=10, 33%), 2 = separation & integration (N= 9, 30%), 3 = integration (N=10, 33%), and 4 = assimilation & integration (N=1, 3%) (see the qualitative analysis section for further details on the categories).

Qualitative Questions

The study's five research questions were explored via open-ended questions. The research questions and responses to the interview guide questions that sought to answer these questions are discussed below and displayed in Table 2.

Research Question One

The first research question was *"What are Hmong elders' preferences for physical, psychosocial, and cultural care during their dying process? (RQ1)"* Participants were asked the following open-ended question (Q14): "*What care would you like if you had an illness that could not be cured?".* If in responding to this question, they did not talk about the care practiced in the Hmong culture or who they would like to provide their care, they were asked the following prompts: "*What kind of care commonly practiced in the Hmong culture would you like to receive? Who would you like to provide the care for you?".*

Research Question Two

The second research question was *"What are the differences and similarities of Hmong elders' care preferences for the dying process base on their acculturation strategy? (RQ2)".* To answer this question, the participants' acculturation strategies were analyzed by using the responses to question and six prompts in section two of the interview guide. The first question in this section, (Section 2, Q12) asked *"What is your life like as a Hmong elder living in the United States?"* I probed with prompts about the importance of practicing Hmong traditions, spending time with Americans, language usually spoken (Hmong or English), who they seek support from, who they usually spend time with, and preferred food (Hmong or American) if participants did not talk about them in their responses to Q12.

Research Question Three

The third research question: *"Have Hmong elders made adaptations in their EOL care preferences and if so, what adaptations have they made? (RQ3)"*, was addressed by asking: *"After having lived in the United States for the past ___ years (say number of years from Q4), do you feel that the care you would have liked to receive when you lived in_____ (insert country) is different than the care you would want now? Would you please talk about why you feel this way?"* (Section 3, Q18).

Research Question Four

The fourth research question is *"What role, if any, do adaptations made by Hmong elders' preferred caregivers play in the elders' care preferences with regard to their dying process? (RQ4)".* In order to answer this research question, I needed to know: 1) who participants preferred as their caregivers, and 2) whether their preferred caregivers have made any adaptations. Learning the participants' preferred caregivers was obtained by the answer to Q14 (Section 3) *"What care would you like if you had an illness that could not be cured?"* and the prompt *"Who would you like to provide the care for you?"* In addition to Q14, answers to Q17 (Section 3), *"If your _____ (respondent's preferred caregiver) could not provide the care for you, who else would you like to give you this care?"* provided knowledge of the participants' preferred caregivers. Information regarding whether the preferred caregiver(s) had made any adaptations were obtained by the responses to Q15 (Section 3) "*You have talked about the types of care you would want to receive if you had an illness that could not be cured. Do you believe you will receive this kind of care? Would you please say more about why you feel this way?"* and Q16 (Section 3) "*You just told me that you would like ____(fill in respondent's preferred caregiver(s) from above) to provide care to you. Do you think that _____(respondent's*

preferred caregiver(s)) will provide this care to you? Would you please say why you feel this way?".

Research Question Five

The fifth research question was *"What role, if any, do Hmong elders' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences for their dying process?"*(RQ5). In addition to providing information to address RQ1, Q14 (Section 3) *"What care would you like if you had an illness that could not be cured?",* also served to inform RQ5. In addition, two prompts to Q14 offered more insight: *"Would you please me about the spiritual beliefs that you have regarding the care you would want if you had an illness that could not be cured?"* and *"Would you please tell me about the spiritual rituals that you would want done if you had an illness that could not be cured?"*. Conventional content analysis was used to analyze the responses to answer RQ5.

Data Analysis

Both qualitative and quantitative methodologies were used to analyze the data. Qualitative data was analyzed using conventional and directed content analysis techniques. Quantitative analyses included descriptive analyses, frequencies, and cross-tabulations.

Prior to conducting the qualitative analyses, audio recordings of the 30 interviews conducted in Hmong and in English were transcribed. For the interviews conducted in Hmong, two steps were taken. I first transcribed the interviews in Hmong and then translated them into English to ensure that translations were accurate (N=23, 77%). I also took the same steps for interviews in which participants used two languages. Seven participants completed their interviews using a mix of Hmong and English (23%). For these interviews, I transcribed word for word with the mix of English and Hmong and translated the Hmong words into English

afterwards so that I did not make any mistakes when translating. By transcribing the interviews, I was able to immerse myself in the narratives. These transcripts were then compared word-for-word to the audio recordings to ensure accuracy of the transcription was completed.

Qualitative Data Analysis

In this study, the qualitative methods conventional and directed content analyses were used to analyze the interview responses. Conventional content analysis is used when limited knowledge exists on a topic (Hsieh & Shannon, 2005). In conventional content analysis, categories emerge from the data rather than using preconceived categories derived from literature. Conventional content analysis is also known as inductive content analysis (2005). This method of content analysis was used to analyze responses for research questions one and five. For research questions two, three and four, a directed content analysis approach was employed. This approach is used when researchers want to test an existing theory with different populations or structure their analysis on prior knowledge (Hsieh & Shannon, 2005). Directed content analysis uses theoretical framework or existing research to determine the initial coding scheme between codes, thus it is more structured than conventional content analysis. Directed content analysis is also described by other researchers as deductive content analysis (2005). In this study, the responses to research questions two, three and four were analyzed using directed content analysis with guidance from Berry's acculturation typology (Berry, 1997, 2005, 2015; Sam & Berry, 2010) and Ward's intercultural adaptation framework (Searle & Ward, 1990; Ward, 2001). Table 2 lays out the research questions, questions from the interview guide that were used to answer the research questions, and the method of analysis utilized.

Table 2

Research Questions, Interview Guide Questions, and Analysis Methods

Research Questions	Interview Guide Questions	Analysis Methods
RQ1: What are Hmong elders' preferences for physical, psychosocial, and culture care during their dying process?	Q14: What care would you like if you had an illness that could not be cured? Q14 Prompt: What types of care commonly practiced in the Hmong culture would you like to receive? Who would you like to provide the care for you?	Conventional Content Analysis
RQ2: What are the differences and similarities of Hmong elders' care preferences for the dying process base on their acculturation strategy?	Q12: What is your life like as a Hmong elder living in the United States? Q12 Prompts: How important is it for you to keep practicing Hmong traditions? How important is it for you to spend time with Americans? What language do you usually speak? Who do you usually go to for support? Who do you usually spend your free time with? Do you usually eat Hmong or American food?"	Directed Content Analysis
RQ3: Have Hmong elders made adaptations in their EOL care preferences and if so, what adaptations have they made?	Q18: After having lived in the United States for the past ___ years (say number of years from Q4), do you feel that the care you would have liked to receive when you lived in_____ (insert country) is different than the care you would want now? Would you please talk about why you feel this way?	Directed Content Analysis
RQ4: What role, if any, do adaptations made by Hmong elders' preferred caregivers play in the elders' care preferences with regard to their dying process?	Q14 Prompt: Who would you like to provide the care for you? Q15: You have talked about the types of care you would want to receive if you had an illness that could not be cured. Do you believe you will receive this kind of	Directed Content Analysis

	care? Would you please say more about why you feel this way? Q16: You just told me that you would like _____ (fill in respondent's preferred caregiver from above) to provide care to you. Do you think that _____ (respondent's preferred caregiver) will provide this care to you? Would you please say more about why you feel this way? Q17: If your _____ (respondent's preferred caregiver) could not provide the care for you, who else would you like to give you this care?	
RQ5: What role, if any, do Hmong elders' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences for their dying process?	Q14: What care would you like if you had an illness that could not be cured? Q14 Prompt: Would you please tell me about the spiritual beliefs that you have regarding the care you would want if you had an illness that could not be cured? Q14 Prompt: Would you please tell me about the spiritual rituals that you would want done if you had an illness that could not be cured?	Conventional Content Analysis

The coding process for this study involved multiple steps between a second coder and myself. The second coder was a doctoral student who self-identified as white, had prior experience with qualitative analysis, and minimal knowledge of the Hmong culture. It was important that the second coder was not Hmong so that my biases and assumptions regarding the culture could be addressed during the coding process. Neuendorf (2009) states that a priori coding qualifications may limit the validity of the coding. This practice of bringing coders with different backgrounds together during the analysis phase has proved successful in addressing researcher influence on coding (Berends & Johnston, 2005). Additionally, the practice of using

multiple coders also ensures reliability. Neuendorf (2002) noted that it is necessary to address reliability when human coders are used to identify themes and referred to this process as inter-coder reliability.

Beginning with conventional content analysis, the second coder and I independently followed the coding process for several transcripts. We began by reading the transcripts to immerse ourselves in the data (Hsieh & Shannon, 2005). Next, we performed open coding, which involved reading the transcripts line by line, highlighting words that captured key concepts, and making notes on the text as they appeared. We also made notes of our first impressions and thoughts during this first step. The notes were collected to create a coding sheet that was used to generate categories and sub-categories. Categories were combined if they were similar (Hsieh & Shannon, 2005). This process was repeated until no further abstraction could be done with the categories. After the coding was completed, we met to compare our results and discuss differences until we reached consensus. Initially, we were at 80% disagreement and further discussion ensued until we reached 100% agreement.

The steps used for the directed content analysis of acculturation strategies and adaptations included the process used by the second coder and myself. One of the first steps to a directed content analysis is to identify key concepts for the initial coding categories (Hsieh & Shannon, 2005). Operational definitions were determined for each category using Berry's acculturation typology framework and Ward's intercultural adaptation framework. Next, we read the transcripts and pulled out text that appeared to represent acculturation and intercultural adaptations. We coded these narratives using the predetermined codes. Any remaining text that could not be included with the pre-determined coding scheme were given a new code (Hsieh &

Shannon, 2005). While we were open to data that did not fit into the acculturation and intercultural adaptation categories in the coding scheme, none emerged.

To conduct directed content analysis of the data for acculturation strategies, I created a coding scheme by using the existing strategy typology (Berry, 1997, 2005, 2015; Sam & Berry, 2010) to determine operational definitions for each category. After the creation of this coding scheme, the second-coder and I used it to analyze several transcripts independently, placing passages under the relevant acculturation strategy (see Table 3) (Hsieh & Shannon, 2005). Next, we met to discuss the differences until we achieved 100% agreement on the coding.

Table 3

Acculturation Strategies and Characteristics

Assimilation	Integration	Separation	Marginalization
Definition	Definition	Definition	Definition
Assimilation refers to the strategy that people use when they do not want to keep their primary cultural identity and identify closely with aspects of their host culture.	The integration strategy is used by people who want to maintain their primary culture while have daily interactions with people from their host culture.	Separation involves maintaining one's original culture and minimizing interactions with people of the host culture.	Marginalization refers to the strategy of people having little interest or possibility of keeping their original culture and have minimal interest in interacting with others as a result of cultural loss, exclusion, or discrimination.
Characteristics:	Characteristics:	Characteristics:	Characteristics:
Preferring American health care[a]	Preferences for both American and Hmong health care[a]	Preferences for Hmong health care over Western[a]	No preferences for either Western or Hmong health care[a]
Hmong traditions are not necessary or not important[b]	Preferring Hmong traditions[b]	Preferring Hmong traditions[b]	Neither Hmong or American traditions are

Eat mostly American food[c] Socializing with more American people than Hmong[d] Mainly speaks English[f]	Being open to American practices[b] Eating both American and Hmong food[c] Socializing with American and Hmong[d] Speaks Hmong and English[f]	American traditions are not important nor necessary[b] Eating mainly Hmong food[c] Socializing mainly with Hmong[d] Speaks mainly Hmong[f]	important or necessary[b] No preferences to Hmong or American food[c] No socializing with Hmong people and no interests in socializing with others[d] Speaks Hmong but little interest in learning or speaking English[f]

Note: This table includes the characteristics used for categorizing Hmong elders' answers to question #12 in the questionnaire.

[a]Refer to articles Geltman et al., 2013; Stewart et al., 2002; Davis et al., 2017. Immigrant acculturation is a predictor of healthcare utilization in host settings. Also refer to Jesilow & Xiong, 2007; acculturation differences in Hmong have impacted how they adjusted to the United States such that some were more well adapted while others faced challenges with maintaining cultural practices such as use of traditional medicine and the desire to live in enclaves.

[b]Refer to articles Jesilow & Xiong, 2007; and Kwak & Berry, 2001 regarding cultural traditions and acculturation.

[c]Refer to articles Anderson et al., 1993, Satia et al., 2001; Satia et al., 2000; and Franzen & Smith, 2008 regarding the impact of acculturation on food consumption.

[d]Refer to articles Lee & Green, 2010; Berry, 1997; and Barry & Garner, 2001.

[f]Refer to articles Anderson et al., 1993; Constantine et al., 2004; Oh et al., 2002; and Lee & Green, 2010.

After using the acculturation coding scheme to conduct directed content analysis and coding of the narratives, participants were assigned the acculturation strategy(ies) that best fit their responses. Past researchers using this typology have measured acculturation quantitatively such that one of four acculturation strategies (assimilation, integration, separation, and

marginalization) was assigned to each participant (Kwak & Berry, 2001; Lee & Green, 2010); however, such was not the case in this study. The data in this study revealed that some participants were using only one strategy while others appeared to be using two strategies. For example, a participant using integration for socialization while using separation for language spoken resulted in their being assigned separation & integration as their acculturation strategies. The resulting strategies assigned to the participants were separation, separation & integration, integration, and integration & assimilation. Throughout this process, the second-coder and I also used constant comparative analysis to compare the categories between the participants. Constant comparative analysis defines the practice of comparing and contrasting every piece of data under study to look for commonalities and differences (Boije, 2002). After checking the analysis several times, it was determined that this categorization was a true representation of the data's diversity.

Having assigned participants their acculturation strategy(ies), I then compared the similarities and differences in care preference themes that resulted from RQ1. The results are displayed in a table on page 88 and entail frequencies for care themes from RQ1 along with participants' acculturation strategies. The frequencies are the number of participants who reported preferring such care and not the number of instances that the care themes were mentioned. In other words, each number accounted for each participant. The percentages are the number of participants who mentioned the care theme divided by the number of participants who reported practicing the acculturation strategies. To compare the care themes based on acculturation strategies, I examined the percentages in each cell and looked for recurring patterns across the acculturation strategies.

After identifying participants' acculturation strategy(ies), we used the same directed content analysis method with the coding scheme seen in Table 4 based on the two categories from Ward's intercultural adaptation framework (Searle & Ward, 1990; Ward, 2001): psychological and sociocultural. We analyzed the passages with a priori codes derived from the literature, such as understanding and accepting reality of situation, and emotions (stress, happy, fear) for psychological adaptations and using mainstream culture's healthcare services, preferring care facilities, and spending time with non-Hmong for sociocultural. Again, we were open to data that did not fit into the pre-established codes, but none were found. This directed content analysis resulted in adaptations related to the participants' care preferences.

Table 4

Hmong Elder Participants' Intercultural Adaptation Coding Scheme

Category	Codes	Others
Psychological Individual's satisfaction and overall emotional or psychological well-being, e.g. depression, stress, satisfaction and acceptance of situation	Understanding and accepting reality of situation Emotions (stress, happy, fear, sad, etc.) Accepts changes in younger generation in the U.S. Accepts reality of younger generation being less aware of traditions	
Socio-cultural How successfully the person acquires the appropriate sociocultural skills for living effectively in the new environment, e.g. behavior problems,	Open to care facilities English language Spending time with non-Hmong Non-Hmong friends, support, or resources	

school achievement, social competence, new language skill	Difficulty with navigating the mainstream society Accepting care at nursing homes Not considering children as caregivers	

The directed content analysis method (Hsieh & Shannon, 2005) used to analyze participants' adaptations with regard to their care preferences for the dying process was also used to analyze their preferred caregivers' adaptations (RQ4). This process was necessary to understand how participants' preferred caregivers' adaptations may have influenced participants' care preferences. We used a coding scheme with psychological and sociocultural adaptation definitions and codes derived from Searle & Ward (1990) and Ward (2001) as shown in Table 5. The difference with this portion of the analysis was that we were looking for participants' narratives related to their preferred caregivers' adaptations. As with the directed content analysis steps above, the second-coder and I separately coded transcripts before meeting to discuss our findings.

Table 5

Participants' Preferred Caregivers' Intercultural Adaptation Coding Scheme

Category	Codes	Others
Psychological Individual's satisfaction and overall emotional or psychological well-being, e.g. depression, stress, satisfaction and acceptance of situation	Understanding and accepting reality of situation in U.S. Emotions (stress, happy, fear, sad, etc.)	
Socio-cultural	Speaks English	

How successfully the person acquires the appropriate sociocultural skills for living effectively in the new environment, e.g. behavior problems, school achievement, social competence, new language skill	Spending time with non-Hmong Non-Hmong friends, support, or resources Difficulty with navigating the mainstream society Employment outside of the home and adaptations related to employment Becoming "Americanized" Not interested in learning Hmong traditions of caregiving

Quantitative Data Analysis

Quantitative data were gathered with regard to participants' demographic information and descriptive analyses conducted to provide information about the sample. Means, ranges, and standard deviations were calculated for age, number of years living in the United States, and overall number of years of education. Frequencies were calculated for the following variables: gender, marital status, country of birth, speak in English, English fluency level, write in English, speak in Hmong, write Hmong, education location (outside and within the United States), employment type, and reasons for not being employed. Frequencies were calculated for type of religion practiced, whether they always practiced the religion, prior religion practiced, and country where the participant was living when they practiced their religion.

Additionally, frequencies were calculated for variables related to whether the participants had always not practiced a religion. For these participants, frequencies were calculated for what

religion they practiced before not practicing any religion. Finally, the variable for the country where the participant was living in when they practiced that religion was also calculated.

Rigor

It is important for qualitative researchers to show the credibility and confirmability of their studies (Lincoln & Guba, 1986). Credibility is truth of the data and the researcher's interpretation and representation of them while confirmability refers to ensuring that the data represent the participants' responses and not the researcher's biases. Several techniques can be used to achieve credibility and confirmability in qualitative research, including member checking and triangulation for credibility and reflexivity for confirmability (1986). Member checking is a process of sharing findings from the data analysis with participants to check for worthiness of the findings (Lietz, Langer, & Furman, 2006). Member checking also allows for the participant to confirm or challenge the accuracy of the data (Patton, 2002). Triangulation defines the practice of using different sources to corroborate evidence that sheds light on themes and provides validity to findings. Reflexivity is defined as critical reflection of the researcher's position and influence in the study, being explicit about their background, and how it influences their interpretation of the data and the results of the study (Patton, 2002).

For this study, I used one technique to member check for credibility. I asked participants at the end of the interview if I could contact them during the data analysis phase for clarification regarding their responses. I presented a summary of preliminary findings to a few participants so they could provide feedback on the accuracy of my interpretation. This summary presentation was offered to participants who were initially recruited through one agency and who were available during the time of the presentation. Before I could present to more participants, the state shut down because of COVID-19, which forced agencies to close their doors to participants.

In this study, I used triangulation by observation, which involved having the second coder conduct data analysis with me (Padgett, 2016) to achieve credibility. By using multiple sources to provide a comprehensive understanding of the phenomenon, triangulation can offer credibility to the study. Doing so can safeguard against bias in data analysis (2016).

In terms of reflexivity, I used memo-writing and journaling throughout the research process (Berger, 2015), to achieve confirmability. Reflexivity allowed me to reflect and understand how my experiences and identity as a Hmong person impacted the study. Reflexivity is particularly important for researchers who study a population in which they hold a membership (Finlay & Gough, 2008). Given that this was true in this study, I used a reflexivity journal to document my thoughts and perspectives throughout the study – particularly after each interview and during the analysis phase – so that I could be conscious of my biases. The journal entries contained my thoughts, feelings, and assumptions as they related to the situation; and steps that I took to limit the influences of my biases on the study.

As a Hmong individual, my connection with the Hmong community and its leaders greatly assisted me in recruiting and interviewing the participants. My ability to speak in Hmong and explain the study in great detail engendered trust from the participants. It was also crucial that I balance when to practice the cultural etiquettes of speaking with a Hmong elder and when to be a researcher so that I was still able to accomplish my goal as a researcher but not harm the elders.

My experience, biases, and understanding of the culture were influential during the analysis phase in such a way that I understood several indirect messages and comments made by the participants, but the second coder did not. For example, I coded the participants' preferences for sons and daughters-in-law as common Hmong caregiving practice because I knew that this

was a tradition in the culture, but the second-coder was less familiar with this practice. Practices such as this one and others similar to it are ones that a majority of people outside of the culture would not know unless they are quite familiar with the culture. Having the second coder served as an essential check-and-balance system not only served this purpose but also achieved triangulation.

Conclusion

In this chapter, the methods used to answer the five research questions posed in the literature review were discussed. The methods were carefully selected and the interview guide developed with guidance from the Life Course Theory (Elder et al., 2003), acculturation typology (Berry, 2005; Sam & Berry, 2010) and intercultural adaptation framework (Searle & Ward, 1990; Ward, 2001), and assistance from researchers with prior research experience with Hmong elders and Hmong elders themselves. The recruitment phase involved the use of purposive and snowball sampling methods because Hmong elders are a hard-to-reach population. As a result, formal and informal referral sources were used in attempt to recruit the participants. For quantitative data, simple descriptive analysis and cross tabulations were conducted while conventional and directed content analysis were used to better understand the qualitative data. To enhance rigor of the study, several methods including member-checking, reflexivity, and triangulation by observation were used and discussed. Findings are synthesized and discussed in the discussion section.

CHAPTER 5: RESULTS

Answers to the five research questions were explored via quantitative and qualitative analyses of the responses to the questions in the interview guide. Descriptive statistics were used to analyze the quantitative data and provide information regarding participants' demographics.

The qualitative analysis methods used were conventional and directed content analyses, and constant comparative analysis.

In this chapter, findings are reported in the following sections: 1) demographics; 2) Hmong elder participants' care preferences for the dying process (RQ1); 3) impact of Hmong elder participants' acculturation strategies on their care preferences (RQ2); 4) Hmong elder participants' adaptations in EOL care preferences (RQ3); 5) Hmong elder participants' preferred caregiver adaptations (RQ4); and 6) Hmong elders participants' care preferences with regard to their religion, spiritual beliefs, and spiritual rituals (RQ5). When reporting the quotes for the qualitative themes, participants' gender is shared only if necessary in answering the research question. Otherwise, the gender pronouns will remain neutral and gender will not be listed with the quotes.

Demographics

Descriptive statistics were run on the demographic variables of the 30 participants and are displayed in Table 6. Twenty (67%) participants identified as female and 10 (33%) as males. The age of the participants ranged from 60 to 89 years with a mean of 69, and positively skewed, which means some participants are much older than the average age. Nineteen (63%) participants were married, 2 (7%) were divorced, and 9 (30%) were widowed. All 19 participants who were married reported living with their spouses. All of the participants had children, with the number ranging from 3 to 11. Almost all participants were living with at least one other person (N=29, 96%). The people living with participants varied and included their spouse only, spouse and children, children and grand-children, and sons and daughters-in-law. The number of years participants had been living in the United States ranged from 5 to 43, with 35 as the average and negatively skewed, which means more participants have been living in the United States longer

than 35 years. All participants were born overseas and had spent some time in Laos before becoming political refugees in Thailand. From there, 3 participants (10%) immigrated to France before immigrating to the United States. The rest (N=27, 90%) emigrated directly from Thailand to the United States. In terms of education, participants reported a range of 0 to 20 years, with the average being 3.8, and the years positively skewed towards more years of education. Twenty out of 30 participants attended school; 2 (7%) did so overseas, 6 (20%) in the United States, and 12 (40%) both overseas and in the United States. When asked about employment, 5 (17%) reported currently working: 1 (3%) as kitchen staff, 2 (7%) as interpreter/bilingual assistant, 1 (3%) as an entrepreneur, and 1 (3%) in manufacturing. Of the 25 who were not currently employed, 1 participant (3%) was laid off, 10 (3%) were on disability, and 14 (47%) were retired.

Language spoken and written differed among the participants. Of the 13 (43%) who reported speaking English, 7 (54%) reported speaking it “a bit”, 3 (23%) speaking “some”, and 3 (23%) “a lot or comfortably”. Ten (3%) of the participants reported they could write in English. Of these 10, 7 (70%) described being able to write “a bit” and 3 (30%) “a lot or comfortably.” All participants spoke Hmong fluently with 14 (47%) of the 30 being able to write it.

Table 6

Hmong Elder Participants’ Demographics

Demographics	N (%)	Mean	SD	Skew	Range (min-max)
Age	30 (100)	69	8.40	.93	60 – 89
Years of education	30 (100)	3.80	4.60	1.71	0 – 20
Children	30 (100)	6.60	2.11	.05	3 – 11
Number of years living in the U.S.	30 (100)	35	8.20	-2.00	5 – 43

Gender	
Female	20 (67)
Country of birth	
Laos	29 (97)
Vietnam	1 (3)
Marital status	
Married	19 (63)
Divorced	2 (7)
Widowed	9 (30)
Location of education	20 (67)
Overseas only	2 (7)
U.S. only	6 (20)
Overseas and U.S.	12 (40)
Employment status	
Kitchen staff	1 (3)
Interpreter/bilingual assistant	2 (7)
Entrepreneur	1 (3)
Manufacturing	1 (3)
Laid off	1 (3)
Disability	10 (33)
Retired	14 (47)
Speak in English	13 (43)
A bit	7 (54)
Some	3 (23)
A lot or comfortably	3 (23)
Write in English	10 (33)
A bit	7 (70)
A lot or comfortably	3 (30)
Speak in Hmong	30 (100)
Write in Hmong	14 (47)
Living with family members	29 (97)

Hmong Elder Participants' Care Preferences for the Dying Process (RQ1)

In this section, the qualitative findings for research question one (RQ1) *"What are Hmong elders' preferences for physical, psychosocial, and cultural care during their dying process?* are presented. The findings include themes and subthemes related to participants' physical, psychosocial, and cultural care preferences, as well as a preference for a quick death (see Table 7). Sub-themes related to the physical, psychosocial, and cultural care domains are reported.

Table 7

RQ1: *Hmong Elder Participants' Care Preferences*

Physical care
Activities of daily living (ADLs)
Bathing
Toileting
Dressing
Ambulating
Instrumental activities of daily living (IADLs)
Provision of care
Psychosocial care
Care with dignity
Kind and gentle communication
Companionship
Cultural care
Hmong beliefs on caregiving
Belief in providing care to elders
Fate
Hmong traditions concerning caregiving
Children traditionally provide care to parents
Caregiver makes decision, not care recipient
Tradition of dying at home
Collectivistic caregiving
Recognition of Western culture's impact on traditional caregiving practices

Prefer quick death

Physical, Psychosocial, and Cultural Care Preferences

The conventional content analysis method was used to address the first research question regarding participants' preferences for physical, psychosocial, and cultural care during their dying process. Participants were asked to think about the care they would like if they had an illness that could not be cured and then to talk about the types of care commonly practiced in the Hmong culture they would like to receive. The analysis revealed major themes as: ADLs, IADLs, provision of care, care with dignity, kind and gentle communication, companionship, Hmong beliefs on caregiving, Hmong traditions concerning caregiving, and prefer quick death. Several of these themes have subthemes that are also reported below. While the question in the interview guide asked participants about the care they would like to receive during their dying process, it did not ask specifically about physical, psychosocial, and cultural care. The analysis, however, revealed themes that fell into these domains, so the results are presented as such below.

Physical Care

Three themes emerged regarding physical care from the data reported by 19 of the 30 participants (63%). These themes were: 1) Activities of Daily Living (ADL)s; 2) Instrumental Activities of Daily Living (IADL)s; and 3) Provision of Care. Four sub-themes of ADLs also emerged: bathing, toileting, dressing, and ambulating. No sub-themes were found with IADLs and Provision of Care.

Activities of Daily Living (ADLs). Twelve of the 19 participants (63%) talked about wanting to receive care with ADLs, which are basic but essential self-care skills, such as bathing, toileting, dressing, eating, ambulating, and grooming (Edemekong et al., 2020). When talking

about the ADLs they would like to receive, participants discussed bathing (N=10; 53%), toileting (N=5; 26%), dressing (N=4; 21%), and help with ambulating (N=4; 21%).

Bathing. The ten participants who talked about preferring bathing as part of their care talked about the importance of such care. For example, one participant stated:

> I would have to have someone take care of me, bathe me…. Think about this. If you haven't passed away yet you still need to be bathed otherwise you would smell bad. Even if I don't want that, I know I won't be able to escape it and would need other people to take care of me.

Toileting. The five participants who talked about receiving toileting as part of their physical care shared that it was essential to receive it when they become dependent on someone else for care. One participant said, "If I could still take care of myself then I'll do it, but if I couldn't…then I would like them [children] to help me [with] toileting..."

Dressing. The four participants who spoke about dressing stated that it was a necessity. One participant reported, "If the elders need to be…dressed…we do, do that. I would like [this] to be done for me… I'd like to receive…dressing daily. I wouldn't like to wear the same outfit for multiple days."

***Ambulating*.** Preference for assistance with ambulating was noted by four participants. One participant shared, "I would want my children to help me…If I could still take care of myself then I'll do it, but if I couldn't, like, if I couldn't walk, then I would like them to help me…"

Instrumental Activities of Daily Living (IADLs). Ten of the 19 participants (53%) spoke about preferring IADLs as part of their EOL care. IADLs are activities that require a more complex process to complete, such as meal preparation, shopping, and medication management

(Edemekong, 2020). These activities are sometimes referred to as those that do not involve the care recipient's physical body as compared to those of ADLs. Ten (53%) participants spoke about meal preparation as a type of IADL care that they would want. As one participant shared, "I would like them to cook food for me and if I don't want to eat anything then that's okay…Food is necessary to thrive. If I can still eat food, I would eat so that I can remain strong."

The participants felt that despite having an illness that could not be cured, it was still important for them to eat. They also felt that the food preparation should consider what kind of food would be easier for the care recipient to consume. One participant stated:

> We believe that if an elder cannot eat anything anymore, we should try to change the food that we give them so that the food is soft or easy for the elder to digest. Even when they have an illness and if it seems like they will not make it, we will still make food for them.

Provision of Care. Five of the 19 participants (26%) who spoke about physical care preferences during the dying process provided details on ways of doing so and preferences regarding who would provide care. One participant wanted the caregiver to keep a constant vigil and watch over them "carefully" and "to stay and be near." Another participant asked that their caregivers "be gentle with me if they need to change me". Three participants talked about modesty as being significant during the dying process and the role gender of their caregivers plays. One male participant stated: "…Because I am a male, when I can no longer clean myself, because of my modesty, I would like for my son to provide the care for me during this time or before I leave this world." A female participant added:

> If my sons do provide the care for me, they can only provide the care such as cooking, transportation, shopping, cleaning, and laundry. When it comes to bathing then, if it's a

> son as the care provider, then it's not likely...If it is females taking care of other females like I said earlier then it is okay because we're alike. Even if there are any embarrassment then we can move pass that embarrassment because they would think "that's just my mom". Plus, I would think that this is my daughter and there is nothing.

Psychosocial Care

Eleven of the 30 participants (37%) talked about types of psychosocial care they would want. These themes included dignity, kind and gentle communication, and companionship.

Care with Dignity. Of the 11 participants who spoke about care related to the psychosocial domain, 3 (N=27%) talked about the importance of receiving care that respects their dignity despite their condition. For example, one participant shared:

> If I had an illness that could not be cured, I would like others to take care of me and believe me that I am truly sick. If I didn't want them to provide care for me, that's different. If I need them to provide the care for me, I would like them to truly provide the care for me honestly.

Kind and Gentle Communication. Eight out of the 11 participants (73%) talked about how caregivers should speak to them during the dying process. They shared that it was important for their caregivers to not speak harshly towards them. One participant said, “Provide good care to me so that I won't be stressed, don't talk harshly to me, speak gently to me so that I won't be stressed so I would want that.” Another participant talked about the ramification of speaking harshly toward the care recipient. They stated, “I would like them to speak gently to me, to not shout, to not talk negatively to me. If you do that, then it makes you, the sick person, become sicker and worst.” One participant, however, talked about how they should be gentle with their communication of needs to their caregivers. They said, “If I don't understand something, I would

ask them gently. I would not scream or yell like others, in some nursing homes, I've seen on YouTube like this."

Companionship. Two (N=18%) of the 11 participants spoke about how important companionship was for them to receive during the dying process. Companionship refers to the company or fellowship that a person has with other people. For one participant, companionship involved needing friends and family members to spend time with them. They stated, "…When you get sick, sometimes you are very lonely. You need somebody. Your friend, your family members… um, people [to] come spend a couple of hours with you…[to] say hi, how are you doing?" The other participant shared the importance of companionship for both the person needing care and the caregivers: "If they want to do any activity, do it with them so they would feel happy so that they can live with the children until they pass away and when they do pass away, the children will be able to be with them."

Cultural Care

Twenty-three of 30 participants (77%) spoke of preferences related to the cultural care domain that they would prefer during the dying process. Two themes emerged regarding the participants' preferences for cultural care: Hmong beliefs on caregiving and Hmong traditions concerning caregiving. Several sub-themes arose under each of these themes and are reported below.

Hmong Beliefs on Caregiving. Out of these 23 participants, 7 (30%) spoke about Hmong cultural beliefs related to caregiving. Two sub-themes emerged: belief in providing care to elders and fate.

Belief in Providing Care to Elders. Three out of the 7 participants (43%) who spoke about Hmong beliefs regarding caregiving shared their belief in providing care to elders. The

participants spoke of a cultural belief, which states that children should provide care to their elders so that they can receive blessings after their elders pass away and be cared for by their own children later on. Elders usually impart their skills, knowledge, and wisdom to those providing care to them and those who are with them when death nears (Bliatout, 1993). Participants explained blessings in the form of good karma such as being cared for by their own children and reaching success. One participant explained karma as:

> There is one thing that Hmong people say and that is that however you treat your parents, your children will treat you that way in the future. Hmong people believe in karma and that if you don't love your parents, you will get karma and your children will mistreat you like how you mistreat your parents.

Another participant explained it this way:

> This is uh a belief in our culture, that if you take care of your elders then you'll receive good karma. If you take care of your elders well, then later on, even if they have passed away, they will leave blessings for you so you'll be successful in whatever you do. For example, you'll get a good job, and your life is better off, like that.

Fate. Four out of the 7 participants (57%) reported that they believed in the role of fate when it comes to receiving care during their dying process. These participants shared that when they have an illness that could not be cured, they would not believe in spiritual causes; instead, they believe it would be their fate to live to a certain age and pass away in a certain way. One participant stated:

> I think that sometimes when the illnesses hit anyone, they would not escape it. I would not believe that my illnesses are spiritually caused and that no one is providing the care

> for me…I would think that is my fate in my life. I would not think that it is because my family did not do shaman rituals to heal me or I am sad, or anything like that.

Hmong Traditions Concerning Caregiving. All 23 participants (100%) talked about Hmong traditions regarding caregiving. Under this theme, several sub-themes related to Hmong caregiving traditions emerged, which included: 1) children provide care to elders; 2) caregiver makes decisions, not care recipient; 3) be at home when receiving care; 4) collectivistic caregiving; 5) adult children as preferred caregivers; and 6) recognition of Western culture's impact on traditional caregiving practices.

Children Traditionally Provide Care to Parents. Out of the 23 participants, 11 (47%) spoke to the tradition of children providing care to their parents as part of their cultural caregiving practices. These participants talked about their children providing care to them like how they (participants) provided care to their elders. One participant shared, "Based on the traditions set by our ancestors and what I would like to receive, when I can't help myself anymore, I would like for my son or daughter to come and take care of me."

Caregiver Makes Decision, Not Care Recipient. Another theme that emerged was the Hmong caregiving tradition of caregivers making care decisions for the elder care recipient. Four of the 23 participants (17%) shared that the type of care they will receive during their dying process will depend on their caregivers' decisions. One participant shared:

> Well for that, I think it depends on [my children] on how they can provide care for me. If they can provide the care as an elder…For example, one of our relatives, when he was very ill and couldn't take care of himself anymore, his son and daughter-in-law took very good care of him. They cooked for him, they bathed him, and they even changed his briefs because he couldn't go to the bathroom by himself anymore. I do think that for me,

it is up to my children. If they can take care of me like that, I am okay with it. If they cannot take care of me then I am okay going to the care facilities.

***Tradition of Dying at Home*.** Four of the 23 participants (17%) discussed the Hmong tradition of dying at home versus in a care facility. One reason for this tradition is so children will be able to be present when their parent passes away. They said, "…keep me at home and not the care facility. I want my children to live with me until I pass away and when I do pass away, my children will be…with me when I take my last breath."

Collectivistic Caregiving. Four of 23 participants (17%) talked about the Hmong tradition of using a collectivistic approach to caregiving. One participant talked about family and extended family by saying, "Uh, the, the unity, the family, there's the bigger family, the extended family. So that is very important…And the uh, connection, the relationship that we have in the Hmong community, in Hmong family is very unique. Because you don't just go from your brothers, sisters, but you go beyond your aunt, your uncle, and extended, you know, great aunt, great uncle. And both sides of the family." Another talked about the importance of family and extended family being present and providing care: "I would say that um, I would still incorporate some of the Hmong traditions. Let's say, it's family care, family be there for me… Family and extended family..." Another participant added that relatives would assist children with caregiving practices, "I can still talk so I would say to them that I want this kind of care and if they know how to provide the care then they would do it. If they don't, they will ask relatives to help."

Recognition of Western Culture's Impact on Traditional Caregiving Practices. When the participants were talking about their care preferences, 11 of 23 participants (48%) spoke about recognizing the impact that the Western culture in the United States has made on what are

traditional Hmong caregiving practices. One participant talked about taking care of themselves and when that is no longer possible, depending on children in a limited fashion. They stated:

> So I would do what I can to the best of my ability and beyond that so I can let somebody else take care of me. But I don't want to depend on my kids…But you need them to be there when you need to but not all the time because some of the Hmong families are oh if you are sick, "I need my kids to be there at all time, not just one but everybody". No, I, they have their own lives so they will be with me at certain times, I understand that.

Another participant talked about not expecting their children to perform cultural care practices or rituals for them during their dying process. The participant stated "I am not expecting them to do anything traditional for me anymore. I don't want them to be troubled with those practices that Hmong people always do." A participant expressed understanding of the differences in their children. They elaborated on the challenges that come with having children who live a different lifestyle in the United States as compared to their lifestyle in their home country. The participant stated that it was important to not impose their beliefs and expectations on their children when it comes to providing care to their elders. They stated:

> Children, children are different from one another, right…If they can't do as you like then I think that it's okay and don't get upset at them. I think we should think that in situations where they can't provide the care based on what you would like, it could be that it's difficult for your children to do it and that's why they're not able to do it.

Prefer Quick Death

When asked about care preferences, 3 of the 30 (10%) participants spoke about wanting a quick death. Two participants shared care preferences but also reported that they would prefer death over not receiving the care they preferred. One participant said, "I would just rather die. I

don't want to be sick and old for people to take care of me. I don't want to be the type of person who has a stroke and someone who is paralyzed." The other participant did not speak about their care preferences because they preferred a quick death. They stated:

> I don't think that I am at that stage yet to be honest with you so that I would know that I would want this or that. You know why I don't think about that? My dream of death is a plane crash… Quick. If one day I pass away and I, um, I don't think, I haven't thought about this or that. I am only thinking about life and death so I don't have the thoughts about the middle part yet. The part where I am terminal.

Summary of Findings for Hmong Elder Participants' EOL Care Preferences

The care themes reported in this section provided insight into the question regarding Hmong elders' preferences for physical, psychosocial, and cultural care during their dying process. Participants spoke of care preferences such as ADLs, IADLs, care with dignity, gentle communication, having companionship, and Hmong caregiving beliefs and traditions. Despite voicing care preferences, especially with regard to traditional Hmong caregiving practices, some participants recognized the impact that the dominant culture in the United States has made on these traditions. As a result of this recognition, participants reported that when they are at EOL, they will not expect their children to adhere to these traditional caregiving practices. Furthermore, three participants spoke of a preference for a quick death.

Impact of Hmong Elder Participants' Acculturation Strategies on their Care Preferences (RQ2)

Research question two (RQ2) *"What are the differences and similarities of Hmong elders' care preferences for the dying process based on their acculturation strategy?"* was addressed by determining the acculturation strategy participants were using and then comparing

the acculturation strategies with their care preferences from RQ1. The questions from the interview guide that were used to determine participants' acculturation strategies involved six prompts following Q12, which asked *"What is your life like as a Hmong elder living in the United States?"* (see Chapter Four for the prompts). The analysis resulted in one to two of Berry's (1997) four acculturation strategies assigned to participants: separation (N=10; 33%), integration (N=10, 33%), separation & integration (N=9, 30%), and integration & assimilation (N=1, 3%). While researchers have assigned one strategy to each participant in previous studies (Barry, 2001; Kwak & Berry, 2001), the results from the analysis in this study showed that some participants were using more than one strategy, which resulted in the two categories that had two strategies: separation & integration and integration & assimilation. Table 8 provides the frequencies for care preferences themes from the first research question and participants' acculturation strategies. The analysis resulted in several differences and similarities with regard to participants' care preferences.

Table 8

RQ2: Acculturation Strategies & Care Theme Comparison

Care themes	Separation (N=10,%)	Separation & Integration (N=9, %)	Integration (N=10, %)	Integration & Assimilation (N, 1%)
Physical care				
ADLs	6 (60%)	2 (22%)	4 (40%)	0
IADLs	5 (50%)	3 (33%)	2 (20%)	0
Provision of care	2 (20%)	2 (22%)	2 (20%)	0
Total	13	7	8	0
Psychosocial care				
Care with dignity	1 (10%)	2 (22%)	1 (10%)	0
Kind and gentle communication	2 (20%)	2 (22%)	4 (40%)	0
Companionship	1 (10%)	0	1 (10%)	0
Total	4	4	6	0
Cultural care				
Hmong beliefs on caregiving	4 (40%)	0	3 (30%)	0

Hmong traditions concerning caregiving	9 (90%)	6 (67%)	7 (70%)	1 (100%)
Recognition of Western culture's impact on traditional caregiving practices	1 (10%)	2 (22%)	7 (70%)	1 (100%)
Total	14	8	17	2
Prefer quick death	2 (20%)	0	0	1 (100%)
Total	2	0	0	1

Differences in Participants' Care Preferences by Acculturation Strategies

The differences in participants' care preferences surrounded their physical care, psychosocial care, and cultural care. Frequencies and percentages are reported.

In terms of their physical care preferences, the differences are with regard to ADLs and IADLs. The one participant practicing integration and assimilation acculturation strategies did not discuss physical care preferences. In regard to ADLs, 6 out of 10 participants (60%) practicing separation reported preferring ADLs while only 2 out of 9 (22%) using both separation and integration, and 4 out of 10 (40%) using integration. Participants' preferences for IADL also mirrored the pattern observed for ADLs. Five out of 10 (50%) participants practicing separation preferred IADL care while only 3 of 9 (33%) participants practicing separation & integration, and 2 out of 10 (20%) participants practicing integration.

With regard to psychosocial care, the main difference seen is in regard to communication. Again, the one integration & assimilation participant did not report any psychosocial care preferences. In viewing Table 8, similarities can be seen in the participants practicing separation, separation & integration and integration, who want care that honored their dignity: 2 of 9 (22%) separated & integrated participants, 1 separated participant (10%) and 1 of (10%) integrated participant. With regard to the preference for kind and gentle communication, however, 4

integrated participants (40%) reported preferring this care while only 2 participants practicing separation (20%) and 2 separation & integration (22%) did so.

The differences with regard to cultural care are related to Hmong caregiving beliefs and traditions. Neither separated & integrated participants or the one integrated & assimilated participant reported caregiving beliefs as important to their care; however, approximately the same amount of participants who practice separation (N=4, 40%) and integration (N=3, 30%) did so. Regarding Hmong caregiving traditions, however, 9 of 10 participants practicing separation discussed wanting these traditions as part of their care, as did the one integration & assimilation participant. The preference was similar for participants practicing separation & integration (N=6, 67%) and integration (N=7, 70%).

In regard to the recognition of the Western culture's impact on Hmong caregiving practices, differences could be seen. Only one participant practicing separation (10%) and 2 (22%) separation & integration reported this recognition. For the participants practicing integration, however, 7 (70%) did so, as did the one participant practicing integration & assimilation.

Differences could also be seen concerning preference for a quick death. Two of the participants practicing separation preferred a quick death if they cannot get their preferred care and the single integrated & assimilated participant who simply stated preferring one. None of the participants who were practicing separation & integration and integration discussed a preference for a quick death.

Similarities in Participants' Care Preferences by Acculturation Strategies

There are just two similarities when comparing the participants' care preferences based on their acculturation strategies. With regard to provision of care, the number of participants who

reported this preference were similar between three acculturation strategies. The separation, (N=2, 20%), separation & integration (N=2, 22%), and integration (N=2, 20%) participants all reported preferences related to the provision of care. The integrated & assimilated participant, however, did not report care preferences related to this theme. In terms of preferring companionship during the dying process, only one of the separated participants (10%) and one of the integrated (10%) participants reported preferring this care. The participants practicing separation & integration and integration & assimilation did not report care related to companionship.

Summary of Differences and Similarities of Participants' Care Preferences

The findings in this section provided insight into how participants' care preferences differed or were similar based on their acculturation strategies. The acculturation strategies that participants were practicing were separation, separation & integration, integration, and integration & assimilation. When examining participants' care preferences through their acculturation strategies, they had more differences than similarities. The differences were with regard to ADLs and IADLS. More separated participants reported ADLs and IADLs than participants using the separation & integration, integration, and integration & assimilation acculturation strategies. Participants' psychosocial care preferences were similar in their wanting care with dignity in that approximately the same number of participants practicing separation, separation & integration, and integration participants preferred this care. More integrated participants, however, preferred kind and gentle communication than separated, separated & integrated and integrated & assimilated participants. While the participants practicing separation & integration and integration & assimilation did not report Hmong caregiving beliefs, participants who were practicing only separation and only integration felt this was important to

them. Although participants all reported preferring traditional Hmong caregiving practices, a larger percentage of participants who were practicing separation and integration & assimilation reported these preferences. Differences were also seen with the number of participants reporting recognizing the Western culture's impact on Hmong caregiving practices and quick death preferences. More integrated participants and the one participant practicing integration & assimilation reported being cognizant of the dominant culture's impact on traditional Hmong caregiving practices than the separated and separated & integrated participants. In terms of similarities, participants who reported practicing only separation, separation & integration, and only integration all reported preferring provisions of care, while the one participant practicing integration & assimilation did not. The same amount of participants practicing only separation and only integration reported preferring companionship during the dying process while the participants who were practicing separation & integration and integration & assimilation did not report preferring this care.

Hmong Elder Participants' Intercultural Adaptations in EOL Care Preferences (RQ3)

One question from the interview guide was used to answer research question three (RQ3) *"Have Hmong elders made adaptations in their EOL care preferences and if so, what adaptations have they made?"*. The question participants were asked was whether the EOL care they would have wanted to receive in their home country was different than the care they would want after living in the United States and if so, why (Q18). Responses to the 'why' portion of this question were analyzed via directed content analyzed using the categories psychological and sociocultural adaptations. Psychological adaptations are related to the satisfaction and overall emotional well-being of an individual (Searle & Ward, 1990; Ward, 2001). Sociocultural adaptation relates to the behavior and skills that people gain in order to live effectively in their

host society (Searle & Ward, 1990; Ward, 2001). The themes displayed in Table 9 provided insight into participants' intercultural adaptations with regard to their EOL care preferences.

Table 9

RQ3: Participants' Care Preferences Adaptations

Intercultural Adaptations
Participants' psychological adaptations
Satisfaction with & acceptance of EOL care provided
Acceptance of care facility as a result of understanding and supporting children's need to work
Participants' sociocultural adaptations
Use of healthcare technology
Use of healthcare options in U.S.
Use of care facilities
Use any kind of care
Reasons for sociocultural adaptations
Caregiving overseas is different from the U.S.
Care is better in the U.S.
Effects of a changed lifestyle
No adaptations made

Intercultural Adaptations

With regard to the question about whether the care participants would have wanted to receive in their home country was different than the care they would want now, 19 of the 30 participants (63%) reported differences in care preferences but 11 (37%) reported they would want similar care regardless of where they live. Eleven of 19 (58%) spoke of being satisfied with and accepting care in the United States, as well as understanding that their children's changed lifestyle may potentially impact their ability to provide care to their elders (psychological adaptations). All 19 participants spoke of preferring care that related to their living in a new

environment (sociocultural adaptation). Six participants reported just psychological adaptations while 13 brought up both psychological and sociocultural adaptations.

Participants' Psychological Adaptations

Two themes related to psychological adaptations emerged for 11 of 19 participants (58%). The first theme was satisfaction with and acceptance of the EOL care they will receive in the United States as opposed to the traditional care they would have received in their home country, regardless of who are the caregivers. The second theme was participants' acceptance of care facility as a result of understanding and supporting their children's need to work.

Satisfaction With & Acceptance of EOL Care Provided

Four out of the 11 (36%) participants reported they would be satisfied with and accepting of the kind of care their preferred caregivers would provide now that their families are living in the United States. One participant talked about not wanting to guilt their children:

> I would not use anything to guilt my children. If my children are able to provide the care for me, I would be okay with it. If they are not, I would be okay with whatever kind of care I get over there [care facility].

Another participant talked about accepting the care that they receive and that they would not impose their Hmong care traditions on their children.

> I think that I should adhere to what is the common practice in this country. I believe that I should not force my practices on them [caregivers at care facilities] and should just accept what their practices are so that it is easier on everyone.

Acceptance of Care Facility as a Result of Understanding and Supporting Children's Need to Work

Seven out of the 11 participants (64%) talked about accepting care facility as a result of being understanding of and supporting their children's need to work to survive in this country. A part of this understanding and support involved not expecting their children to provide the care for them during their dying process and to be open to going to a care facility. One participant shared:

> Yes, for myself, I think that when I am at end of life, I would not want my children to provide the care for me. I would not want to take away their time. I don't want them to miss work. It's hard for my children. In this country, we [Hmong elders] should understand that when we are sick and we can no longer take care of ourselves, we should, this country has care facilities to help so we should go there.

Another participant shared that in addition to understanding and supporting their children's employment requirements, they also do not want to become obstacles to their children.

> If it is not the nursing home, I will become an obstacle for my children and they wouldn't be able to go to work. Anyway, I am going to pass away. It's not that if my children provide care for me then I will become better. In any way, I will pass away.

Another participant stated that not only would they be accepting of living in a care facility, they would also not be emotionally affected by doing so. They elaborated by saying, "I would not be saddened by my sons' or daughters' lack of care towards me during this time. I think that they have to work a lot but there is help and care available at the care facilities."

Participants' Sociocultural Adaptations

Nineteen out of 30 participants (63%) spoke about preferring to use other care options now that they are living in the United States. Four themes emerged regarding EOL care preferences, which involved participants preferring to use: current healthcare technology; health care options in the United States; care facilities; and any kind of care available.

Use of Current Healthcare Technology

Two out of the 19 participants (10%) talked about being open to receiving Western technology as part of their care during the dying process. They compared the differences in caregiving overseas to that in the United States where technology is available. The participant stated, "Taking care of an elder in Laos is very difficult because there are no technology to help take care of the elder. So I would want the technology, like the wheelchair, a walker, and good medicine."

Another participant talked about the difference that the technology would offer them during the dying process as compared to what it would be in their home country.

> Because back in the old country, let's say Laos or Thailand, maybe they just provide you with shelter, they might just provide you with medicine, or they might just come and give you some basics. So no technology help but in the United States, there are more technology, more new things to help you. The comfort would be much better. The care level would be much different for me. But the intention would probably be the same but the variety, the options, there are more options in the United States than in the old country, Laos or Thailand.

Use of Healthcare Options in United States

Eight out of the 19 participants (42%) shared that there are resources such as programs, nursing homes, home cares, and other services that they would be open to receiving as care options. One stated:

> Well, in this country, if you can get services from programs such as this one [Hmong adult day center] and for those who are very sick, there are doctors that could help you and help manage your illness and have people provide the care for you. Overseas, you don't really have anyone to help you and help manage your illness or help provide the care for you.

Two of the eight participants (7%) talked about including the care options in the U.S. with the care that they would receive from their family and/or children as caregivers. For example, one participant said, “I would say that um, I would still incorporate some of the Hmong traditions. Let’s say, it's family care, family be there for me, but I would also take some of the Western culture.”

Another participant stated:

> In this country, there are many services and resources to help. My children can provide the care for me such as cooking for me and if there is anything that they can't do then they can help get the services for me so it's not as hard.

Use of Care Facilities

Ten of the 19 participants (52%) talked about using care facilities during their dying process. One participant stated, “Just take me to the nursing home and have them take care of me…Whatever the rules they have over there, whatever they do, I'd be okay with it.”

Another participant stated that although the tradition is that their children would provide the care for them, and if that was not an option, they would live in a care facility. They stated:

> Because overseas, the lifestyle is different. The difference is that we don't have anything to help us. All we know is that we have that one care provider to help us and cook for us, look out for us like that. If you get that, that's all. If you don't have it, then your life would be very difficult and very harsh. Over here, if we don't have the children to provide care for us then there are care facilities that we can go to.

Use Any Kind of Care

Four out of the 19 (21%) reported that they do not have any specific care that they would like and are open to receiving any care that their caregivers offer. One participant said, "I don't know how my life will be like at that time. I may need someone to help me at that time and I guess at that time I will take whatever kind of care I need."

Reasons for Sociocultural Adaptations

Nineteen of 30 participants (63%) compared the lifestyle and caregiving in their home countries to those of the United States and reported why they would prefer care differently base on the country in which they live. The themes included that of caregiving in their home country being different from that provided in the United States, care being better than that provided overseas, and lifestyle being different in the United States compared to how it was in their home country.

Caregiving Overseas is Different from the United States

Fourteen of the 19 participants (73%) shared that caregiving overseas is different from caregiving in the United States. Participants shared that low quality of caregiving in their home country made it challenging for caregivers to provide good care to their elders. Other differences

that were mentioned included lack of equipment availability and resources overall to assist with caregiving. One participant stated:

> Well, because overseas, there is no good services or places for you to take good care of your elders…There is no lift machine to use so you can bathe the elder. When they are ill and cannot take care of themselves, and need bathing and toileting, if you have children who love and care about you, then they would help clean you while you were on your bed. In this country, there would be lift machines that can help you lift the elder…

Care is Better in the United States

Four of the 19 participants (21%) talked about how the care is not only different but it is better in the United States. A participant stated, "In this country, it is very different… Different because what I want, in this country, even if I were to pass away, the care that they would provide for me would be much better than overseas." Another participant added, "Over here, you are better off. If you live overseas, if you are sick, you just wait until you die. There is no such thing as getting care to help you get better…The healthcare is not good."

Effects of A Changed Lifestyle

One out of 19 participants (5%) talked about how living in a different country and lifestyle influenced their change in care preferences. The participant reported:

> I know that it is just what my heart desires, I am sad that my children will not have time to provide the care for me every day. This is because of the lifestyle here where their work life is different from ours back then. What I am hopeful for is that even if I do end up living in a care facility at end of life, I would like for my children to come and visit me.

No Adaptations Made

Eleven out of 30 participants (37%) reported no changes regarding the care they would want for their dying process. They stated that per Hmong traditions they would still want their children to provide their care regardless of where they live. For example, one participant explained that she would like to receive the same kind of care that she gave to her mother-in-law despite living in another country.

> Whether I'm living overseas or here, if my children can take care of me like how I was able to take care of my mother-in-law then I would not want to live in a nursing home…I would rather live at home for them to help take care of me because after a long day, they will still come check on me. If you live in the nursing home, weeks could go by and they might not even come visit you.

Another participant spoke about still preferring their children to provide the care to them. This participant said that the only difference would be the lack of support that their children would receive if they were not living in a country, such as the United States, where caregiving resources are available.

> It wouldn't be different. I would still like my children to provide the care to me. The care overseas would be limited in that the children would not have support or services like how they do here in the United States such as nurses and doctors to check on you…

Summary of Findings for Adaptations in EOL Care Preferences

The findings in this section provide a deeper understanding of the intercultural adaptations participants have and have not made with regard to care preferences for the dying process. About two-thirds of the participants reported having made psychological and/or sociocultural adaptations with regard to their care preferences. The psychological adaptations

participants made were related to their children needing to work out of the home. Participants would be satisfied with and accepting of the EOL care they would receive. They would be accepting of living in a care facility because they understand and support their children's need to work. The sociocultural adaptations participants made were related to being open to the care options in the United States, such as the technologies, care facility, and any kind of care available. The remaining one-third who reported to have not made any adaptations felt that regardless of which country they lived in, they would prefer the same type of EOL care. They attributed this decision to their belief in Hmong traditions such as their children providing care to them. The findings in this section shed light on the heterogeneity within participants' care preferences for the dying process.

Hmong Elder Participants' Preferred Caregivers' Intercultural Adaptations (RQ4)

The qualitative directed content analysis method was used to address research question four (RQ4) *"What role, if any, do adaptations made by Hmong elders' preferred caregivers play in the elders' care preferences with regard to their dying process?"* In the interviews, participants were asked whether they believed they would receive the EOL care they want to receive and why they felt this way. They were then asked whether they thought their preferred caregivers would provide this care to them and why or why not. Participants' responses to the "why or why not" for both questions were analyzed via directed content analysis using psychological and sociocultural categories (Searle & Ward, 1990; Ward, 2001). Finally, participants were asked who their preferred caregivers were, and if their preferred caregivers could not provide the care, who else would they like to do so. These questions were asked to determine if adaptation had been made in regard to who they prefer as their caregivers. Themes are reported below with exemplar quotes.

Participants reported their preferred caregivers being their children, spouse, care facility, and having no preference. A majority of the participants (N=24, 80%) preferred their adult children as their caregivers. One (3%) participant reported that they preferred their wife and children. Four (13%) preferred care facilities, and one (3%) reported that they had no preference with regard to their caregivers.

Exploring Whether Participants Believe They Will Receive Their Preferred Care

In response to the close-ended question about whether participants believed they would receive the care they want, 8 out of 30 (26%) shared that they do not know, 7 (23%) said they would not, and 15 (50%) stated they would. Themes that emerged from the directed content analysis of the explanation participants gave are discussed below and can be found in Table 10.

Table 10

RQ4: Impact of Caregivers' Intercultural Adaptation on Participants' Care Preferences

Participants' preferred caregivers
Adult children
Spouse and children
Care facility
No preference
Participants' beliefs regarding receiving their preferred care
Do not know whether they will receive their preferred care
Not yet terminal
No care expectations
Unsure whether preferred adult child caregivers will care about elders
Do not believe they will receive their preferred care
Preferred caregiver's sociocultural adaptation
Children showing lack of care for elders
Believe they will receive their preferred care
Preferred caregiver's adaptation has no effect
Participant psychological adaptation

Participants' thoughts regarding receiving preferred care from preferred caregivers
Do not know whether preferred caregivers would provide preferred care
Impact of children's sociocultural adaptation
Unsure whether preferred adult child caregivers will want to provide care
Participant psychological adaptation
Do not think they will receive preferred care from their preferred caregivers
Preferred adult children caregivers' sociocultural adaptations
Participant Psychological adaptation
Preferred caregivers will provide preferred care
Preferred adult child caregivers will provide care
Participant Psychological adaptation
Participants' alternative caregivers
Formal Hmong caregivers
Informal Hmong caregivers
Care facility
Do not want alternative caregiver
Do not know
If not children, prefer death

Do Not Know Whether They Will Receive Their Preferred Care

For the 8 participants who stated they did not know whether they would receive their preferred care, three themes emerged: not yet terminal, no care expectations, and unsure of whether their preferred adult child caregivers will care about them.

Not Yet Terminal. Two out of eight participants (25%) said they did not know whether they will receive their preferred care because they do not currently have an illness that could not be cured. One participant stated, "I think that I would like to receive it as my heart desires but…I am not at the point where I am sick yet so I don't know..."

No Care Expectations. Three of the 8 participants (38%) spoke about not having care expectations. They talked about having no care expectations as being unsure whether they will receive the specific care they prefer and as a result would be open to any kind of care they will

receive. One participant said, "…I will be okay with whatever kind of care I get at the nursing home…I'm not sure if they will be able to provide the specific care I want but I will be okay with what I get."

Unsure Whether Preferred Adult Child Caregivers Will Care About Elders. Three participants out of 8 (38%) shared that they do not know whether their children, who are their preferred caregivers, will care about them at that time. They stated, "The children, you may have many of them but there may be just one or two who really care about you…My four sons…they don't call me…until, several years...But for my daughters, every couple of weeks, they will call…"

Do Not Believe They Will Receive Their Preferred Care

Two themes emerged from the responses reported by 7 participants who stated they did not believe they would receive their preferred care. These themes were preferred caregiver's sociocultural adaptations and children showing lack of care toward elders.

Preferred Caregiver's Sociocultural Adaptation. Three of the 7 participants (28%) talked about how adult children must work in the United States and doing so may limit their ability to care for them. One participant stated:

> The part about receiving the kind of care that you desire will be minimal, because our children in this country all work…They work and if they come and provide care for me, they might lose their job. They might lose their job and their job is what will sustain them.

Another participant said that their children's new American lifestyle has impacted their ability to care for them as they traditionally would have: "Our children want to live like Americans but we elders want to live with our children like how our traditions have been."

Children Showing Lack of Care for Elders. Four out of the 7 participants (57%) shared that they do not believe they will receive their preferred care because they see that their children, who are their preferred caregivers, are showing a lack of care towards them. One participant elaborated, "…My children are already showing me that they won't provide the care to me. They don't really check in on me and my spouse so I think that it's likely I will not receive the care I want."

Believe They Will Receive Their Preferred Care

Two themes emerged for the 15 participants who believed they would receive the EOL care they desired: preferred caregiver's adaptation has no effect on care preferences and participant's psychological adaptations.

Preferred Caregiver's Adaptation Has No Effect. Thirteen of the 15 (87%) participants believed that although their preferred caregiver's lifestyle had changed since moving to the United States, it would have no effect on receiving their desired care. These participants shared that their caregivers would be their children. One participant shared, "I do believe that all of my children will be able to provide the care for me…My daughter-in-law is from a different clan but because she is married to my son, she does care about me, too…"

Participant Psychological Adaptation. Two of the 15 participants (13%) reported they believed they will receive their preferred care because they would be satisfied with receiving any kind of care. For example, one participant stated, "Because like I said, I am not expecting anything from my children or from anyone. I would be happy with whatever kind of care I receive whether it's from my children or at the nursing home."

Exploring Whether Participants Think Their Preferred Caregivers Would Provide Preferred Care to Them

The participants' responses to the close-ended question regarding whether they think their preferred caregivers would provide them with the care they want revealed that 12 of the 30 participants (40%) did not know, 14 (46%) believed so, and 4 (13%) did not. Themes that emerged from the directed content analysis of the explanation are reported below and displayed in Table 10.

Do Not Know Whether Preferred Caregivers Would Provide Preferred Care

For the twelve participants (40%) who spoke about being unsure whether their preferred caregivers will provide care for them, the analysis resulted in three themes. These themes include: recognition of Western culture's impact on care elders will likely receive, unsure whether preferred adult caregivers will want to provide care, and having no care expectations.

Impact of Children's Sociocultural Adaptation. Eight of the 12 participants (67%) spoke about how their preferred caregivers' lifestyles in the United States have impacted their ability to provide care to them (the participants). All eight participants' preferred caregivers were their adult children. They spoke of their adult children having to work in order to sustain their lives. One participant stated, "I don't know if any of them, daughters or son, will provide the care for me…In this country, you have to work hard to earn a living...because of that, they won't be available to provide the care for me…" Another participant spoke of their adult children as being "Americanized", and said, "I think that because my children are Americanized so when I am not able to provide care myself and…would need them to help change me…I know they would not want to." Another participant noted having observed their children showing a lack of interest in learning the Hmong traditions, especially regarding caregiving. They said, "Now our children

don't even want to go and learn how to provide good care to our elders so it would be very difficult for us to receive the care that we want."

Unsure Whether Preferred Adult Child Caregivers Will Want to Provide Care. Five of the 12 participants (42%) noted their uncertainty regarding whether their preferred adult child caregiver will want to provide care to them. One participant shared:

> Right now, my children who are not married, do listen and help me. But when they are married and have in-laws, it's uncertain if they will remain the same and help you. For daughters, after they marry, they are going to live with their in-laws, and sons and daughters-in-laws, if you ask for help from daughters-in-law, they may say "Why are you always asking me to do things for you?" So you may not get what you desire.

Participant Psychological Adaptation. Two of the 12 participants (16%) shared that they have no expectations for any specific care during their dying process. One participant spoke of empathizing with their preferred adult child caregiver as they could not provide the care to their own spouse. They said:

> During that time, I think that…my children would not want to provide the care for me…Even me as an elder, I could not provide the care [to my spouse], so I would not be sad if my children cannot do it…If they are able to do it, great. If they cannot provide the care, then I would not be sad.

Another participant shared that they should not expect any kind of care and be open to receiving any care, including living at a care facility. They were understanding of their preferred adult child caregiver's need to work, and how that could compromise their ability to provide care. This participant shared:

> I am not expecting any specific types of care. For me, I am not afraid of going to the nursing homes. I think that as an elder, you should not expect your children to provide the care for you because they have to work...

Do Not Think They Will Receive Preferred Care from Their Preferred Caregivers

For the four participants who reported thinking that their preferred caregivers would not provide their preferred care to them, two themes emerged from their responses. One theme was their preferred adult child caregivers' sociocultural adaptations and the other was the participants' psychological adaptations.

Preferred Adult Child Caregivers' Sociocultural Adaptations. Three of the four (75%) participants shared that they do not believe their preferred adult child caregiver will provide the care they want due to their current behavior. The participants shared that currently, their children are showing lack of care towards them so they do not think they will receive their desired care. One participant said, "Because nowadays I already know that even when I am still independent now, they don't even come and check-in on me. It's always me asking about them. They only call me when they need a babysitter." Two participants shared that the work demands and responsibilities their children now have in the United States can require them to relocate for their job. For example, "My children, I would like them to provide the care to me but they work so they have to go their own ways…They have to follow their careers so they go wherever their careers take them..."

Participant Psychological Adaptation. One participant (25%) shared that they felt they would not have control over the care they received and in believing so, would be accepting of any kind of care. They said, "Well, if you haven't taken care of someone before, it will be hard.

And like I said earlier, I don't know what will happen at that time and I can't control how they will provide the care for me so I would be okay with whatever I get…"

Preferred Caregivers Will Provide Preferred Care

The analysis revealed two themes from the responses of the fourteen participants who reported thinking that their preferred caregivers will provide the care as they preferred. All 14 participants reported their preferred caregivers were their adult children. One theme was preferred adult caregivers will provide care and the other was participants' psychological adaptations.

Preferred Adult Child Caregivers Will Provide Care. Twelve out of the 14 (86%) participants thought their preferred adult child caregiver would provide the care they preferred. One participant shared:

> Yes. Later on, I do believe that my children will not forget about me even when I can no longer take care of myself or have an illness that could not be cured. If I have not passed away yet then I know that they will not forget about me, that they will love me and provide the care for me.

Participant Psychological Adaptation. Two of the fourteen participants (14%) discussed making changes with regard to their care preferences by being open to any care that they will receive during the dying process. One participant said:

> I will be okay with whatever I get from the care facility…If my children don't provide the care for me, I would not be sad. I will be happy with what I get from the care facility. I will not expect anything more or force my traditional practices from my culture onto the care providers at the nursing home.

Participants' Alternative Caregivers

In an attempt to further understand how the participants' preferred caregivers' adaptations may impact participants' care preferences, a question was asked regarding who they would like as an alternative caregiver if their preferred caregivers could not provide care. Participants talked about alternative caregivers being formal Hmong caregivers, informal Hmong caregivers, and care facilities. Participants also reported having no alternative caregivers, not knowing who their caregivers would be, and preferring death over not having their children as their caregivers. Table 10 contains the themes, which are also reported below with exemplar quotes.

Formal Hmong Caregivers. Four of the 30 (13%) participants stated that as an alternative they would like to receive caregiving from formal Hmong caregivers because of language and modesty issues. They identified these alternative caregivers as Hmong professionals from outside of the family whose job is to provide care to others. One participant stated, "Find someone outside of the family. As long as it is someone outside of the family like those people who are health care professionals and provide care for elders for a living. I would prefer Hmong people."

Another participant elaborated that they preferred Hmong formal caregivers as an alternative because of the language barrier. They said, "I would like someone outside of the family to provide care for me…They must be Hmong because I…don't know the English language so if it's not a Hmong care provider, it would be very hard for me."

In addition to language, a female participant stated they would prefer formal Hmong female caregivers because of their preference for a same-sex caregiver. She stated:

> I am the type of person who is very modest…If [my children] don't want to [provide care to me]…I would be okay with a Hmong nurse…That is because we are the same [gender]. If I like to be cared in a certain way, I would be able to tell them…I would be able to tell them and they can do it for me.

Informal Hmong Caregivers. Three (10%) of the 30 participants talked about preferring informal Hmong caregivers as alternatives. They talked about choosing other people such as their family, relatives, and friends if their preferred caregivers are not able to provide the care for them. One participant stated that, "If my children cannot provide the care for me, I would be okay with someone outside of the family… Well, like my sisters, or cousins, or other relatives, or friends." Another added, "I would say my siblings but because I am the youngest, I hope that they're still around… Yes, still family."

Care Facility. Sixteen of the 30 participants (53%) stated if they could not have their preferred caregiver, their alternative would be living in a care facility. Additionally, these participants stated that they would be accepting of the care provided at the facilities. One participant stated, "Oh, I was thinking that when my children cannot care for me anymore, I guess I would be okay with going to the hospital, the nursing home, and just accept whatever kind of care these facilities can offer."

Another participant stated that they are grateful for care facilities as alternatives to their children providing care for them. They stated, "I am happy that…There are care facilities to help. I think that the care facilities offer a huge relief to the children. It's a huge relief for the children and for the sick or elderly and for myself."

Do Not Want Alternative Caregivers. When asked about alternative caregivers, 3 of the 30 (10%) still would like the same caregiver: children and care facility. One participant said,

“For me as a male, I would want my sons.” Another participant reported that their preferred caregivers are their children and if they cannot provide the care for them, they would not have any other options and would still prefer their children. They stated, “When you don't have a choice, you just go back to your children. For the children to provide the care for you.” Another participant said, “I guess I would go to a different nursing home. Like I said earlier, there are many nursing homes so I guess it would be a different one.”

Do Not Know. Two of the 30 (10%) participants talked about not knowing who their alternative caregivers would be if their preferred caregivers could not provide the care for them. One participant stated, “I'm not really sure because I know that my children won't be available and most likely my relatives would not be doing the caregiving either so I don't know.”

If Not Children, Prefer Death. Two participants (7%) stated that if their preferred caregivers, who are their children, could not provide the care for them, they would not have any other options. One participant stated, **“**Uh, when my children can't take care of me anymore, I would rather just die. If my children can't provide care for me, I would just live by myself until I pass away.”

Comparison of Preferred Caregivers to Alternative Caregivers

Adaptations with regard to caregivers were seen when comparing participants’ preferred caregivers to their alternative caregivers. While a majority of participants preferred their adult children as caregivers, when compared to alternative caregivers, a majority of participants would like to use care facilities. Participants reported more alternative caregivers than preferred caregivers by stating they would like formal Hmong and informal Hmong alternative caregivers. Some participants felt that they did not want alternative caregivers while others did not know who would be their alternative options. A couple of participants felt that if they did not have their

children as their caregivers, they would rather choose death. Overall, the comparison showed that some participants would be open to other caregiver options if their preferred caregivers could not provide care to them.

Summary of Findings for Preferred Caregivers' Adaptations

The findings in this section provided understanding of the role participants' and their preferred caregivers' adaptations play in receiving their preferred care for the dying process. Participants reported their preferred caregivers being their adult children, spouse, care facility, and having no preference. Participants had different beliefs regarding whether they would receive their preferred care and thoughts about whether their preferred caregivers would provide this care. Some participants felt that they were not terminally ill yet and had no care expectations while others recognized that their preferred adult child caregiver's job and career would be at risk if they served as their caregiver so would be satisfied with any kind of care they receive (psychological adaptation). Others reported their preferred adult child caregivers showing lack of care towards them (participants) and other adaptations that these adult child caregivers have made. Some participants made psychological adaptations in response to their preferred adult child caregivers' adaptations. Other participants, however, believed their adult children would still provide care for them regardless of the situations in which they are living. For other participants who did not believe so, they spoke of alternative caregivers such as informal Hmong caregivers, formal Hmong caregivers, and living in care facilities, and two preferred death over not having their children as their preferred caregivers. The comparison of participants' preferred caregivers to their alternative caregivers provided further understanding of participants' adaptations in response to their preferred caregivers being unavailable to provide care to them.

The findings showed that participants would be willing to consider caregivers such as formal caregivers and care facilities aside from their adult children.

Hmong Elders' Care Preferences with Regard to Their Religion, Spiritual Beliefs, and Spiritual Rituals (RQ5)

The qualitative conventional content analysis method was used to answer research question five (RQ5) *"What role, if any, do Hmong elders' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences for their dying process?"* In order to answer this research question, questions were asked to garner an understanding of the participants' religious practices and their spiritual beliefs and rituals. A series of close-ended questions were asked regarding the participants' religious practices. Participants were asked what religion they were practicing and if they had always practiced it; if they were practicing a different religion before their current one, what religion it was and what country they were living in at the time; if not practicing a religion, had they always done so; and if practicing a religion before not practicing one, what it was and the country they were living in a that time. In addition to these questions, participants were asked two-open ended questions about their care preferences with regard to their spiritual beliefs and rituals. Conventional content analysis was used to analyze this data.

Religion

Half of the participants (N=15, 50%) reported practicing Christianity, fourteen (47%) Animism, and one (3%) reported not practicing any religion. Religion was dichotomous for all the participants. In other words, no participants talked about practicing both religions. The one participant who reported not practicing any religion was practicing Animism while living in Laos and Thailand and when they first moved to the United States but is no longer doing so. Of the 29

participants practicing a religion, 16 (55%) had always practiced that same religion, while 13 (43%) reported having practiced a different religion prior to their current one. Of the 13 who reported having practiced a different religion, one (7%) reported having practiced Christianity in Laos and Thailand but converted to Animism after marrying an Animist husband and is still practicing this same religion in the United States. The 12 (93%) who had once practiced Animism and now practiced Christianity, came from a variety of countries, including Laos and Thailand. Upon moving to the United States, they converted to Christianity, their sponsors' religion.

Spiritual Beliefs

When asked about their spiritual beliefs regarding their preferred EOL care, 14 of 15 (93%) Christian participants spoke about Christian beliefs and the other stated they did not have any spiritual beliefs regarding their care preferences. All 14 Animist participants and the one non-practicing participant spoke of Animist spiritual beliefs regarding their care preferences for the dying process. No Christian participants mentioned having any Animist spiritual beliefs regarding EOL care. Additionally, no Animist participants, particularly the one who converted from Christianity to Animism, spoke about preferring Christian spiritual beliefs regarding their EOL care preferences. The spiritual beliefs regarding care themes for Christian and Animist participants are discussed below and reported in Table 11. The Christian spiritual belief themes were prayers as part of care and responsibilities for elders. Animist spiritual belief themes included: belief in a spiritual cause of illness; belief in rituals as care practices to heal illnesses or extend life; fate; integration of Western and Hmong beliefs; and anti-animist beliefs.

Table 11

RQ5: Spiritual Beliefs & Rituals with Regard to Care Preferences

Spiritual beliefs
Christian beliefs regarding care for the dying process
Prayers as part of care
Responsibilities for elders
Animist beliefs regarding care for the dying process
Belief in a spiritual cause of illness
Belief in rituals as care practices to cure illness or extend life
Fate
Integration of Western and Hmong beliefs.
Anti-animist beliefs
Spiritual rituals
Christian rituals regarding care in the dying process
Praying
Church involvement
Animist rituals regarding care in the dying process
Shaman rituals done to diagnose illness
Shaman rituals done to heal
Soul calling
Children to arrange and/or perform rituals
Psychological adaptation
Integration of Western and Hmong care

Christian Beliefs Regarding Care for the Dying Process. Eleven out of 14 Christian participants (73%) talked about particular Christian beliefs regarding care preferences if they had an illness that could not be cured. Two themes emerged: prayers as part of care and responsibilities for elders. Two sub-themes emerged under the prayers as part of care theme: prayers help relieve stress and pray to be with God.

Prayers as Part of Care. Ten of the 14 Christian participants (71%) stated that they believed in the power of prayers and would like prayers as part of their preferred care during

their dying process. One participant said, “I don't know. It would just be believing in the power of praying to God.” Another participant talked about their own beliefs regarding the importance of prayers and noted the difference with regard to an Animistic belief. They stated, “For those who go to church, there is really just the belief of praying. Praying to God to help and whatever happens, happens. It's not like Animism where one would do soul calling, spiritual offerings, or shaman rituals.” One participant spoke about their belief that prayers during their dying process would help with relieving the stress from being ill. She said, “Yeah, it would make me stress less about my illness and that God is watching me….” Seven participants talked about their belief that prayers during the dying process will bring them closer to being with God after death.

Responsibilities for Elders. Three out of 14 Christian participants (21%) talked about their belief in loving and providing care for their elders. One participant stated:

> For Christians, we believe that we love and care for our elders. This teaches us that we have responsibilities to take care of our parents. Yes, they can take care of themselves when they are able to but when they are not, it is my turn to take care of them.

Animist Beliefs Regarding Care for the Dying Process. All 14 Animist participants and the one participant who was not practicing any religion spoke of Animist beliefs regarding their preferred care for when they have an illness that could not be cured. These beliefs include spiritual causes of illnesses, rituals done to heal illness or extend life, fate, integration of Hmong and Western beliefs, and anti-animist beliefs.

Belief in a Spiritual Cause of Illness. Nine out of the 15 (60%) participants reported that they believed in spiritual causes of illnesses. This belief stems from Hmong Animists’ beliefs that the soul is a part of the body and when the soul has become detached, an imbalance occurs, which results in illness (Plotnikoff et al., 2002). As a result of this belief, Hmong Animists

believe in providing care that is spiritually related, such as doing spiritual rituals, despite someone's terminal condition (Culhane-Pera, 2003). One participant explained the belief:

> Well, Hmong have the belief that your soul is connected to your body. When your soul is no longer with your body because of some incidents that cause the soul to leave such as being scared or being very sad, then you have to do a ritual that would help the soul come back. Those rituals are the ones that I said like soul calling or doing a shaman ritual to try to cure the person. When the soul is back with the body, the person will become better and better each day. Hmong people believe this because they have seen this in the past.

Another participant talked about their belief in finding out if soul loss was the reason for someone's illness. The participant stated:

> If I am sick and you [shaman] come to diagnose me first saying it could be a soul loss then after a few days I get better, that means that I would like you as the shaman to come back and do a ritual to try to heal me. So that's the belief.

Belief in Rituals as Care Practices to Heal Illness or Extend Life. Eight out of 15 (53%) participants talked about their belief that despite someone having an illness that cannot be cured, care practice rituals should still be done in an attempt to heal or extend the person's life. One of the participants stated:

> I would like them to do shaman rituals to see if there is anything wrong. If there is anything wrong with me and they should do the rituals to make me better. For example, if they find out that my illness is due to a soul loss then they should do a soul calling. If I am sad or have been scared from other things then they should do shaman rituals to try to cure me so that I feel better.

Another participant said:

> Soul calling and shamanic rituals to cure me. I would like these. I want these because this is our tradition that our elders have always done. If we do these traditions, if my children do them for me then I would be happy, my soul would be happy then I would be happy.

Fate. Four of the 15 (27%) participants talked about their belief in fate and how it influences their care preferences. The participants said they believe that if their fate is that they are meant to live to a certain age, no amount of rituals or treatment would extend their lives. As one participant stated:

> Well, spiritual beliefs and rituals, like I've said before, when you are going to pass away for real, they will not help you. When it is your time to go [pass away], no matter what, they will not help you. However, if it is not your time to go yet and you are still going to live then the spiritual beliefs and rituals will help you.

Integration of Western and Hmong Beliefs. Two of the 15 (13%) participants stated they preferred care that integrates Western and Hmong beliefs during the dying process. One participant stated:

> Mm, spiritual beliefs, for example, if your children, if you are sick, like my mother-in-law and my husband. If they are sick, you can't see that there is anything wrong spiritually but when you take them to the doctors and if the doctors can diagnose what illnesses they have then you can do shaman rituals and do soul calling and you also do spiritual offerings.

Anti-Animist Beliefs. Three out of 15 participants (20%) shared that they do not believe in Animist spiritual beliefs as part of their care during the dying process. One participant stated:

> I would not believe that it is because of my spirits and that's why I am sick. I think that sometimes when the illnesses hit anyone, they would not escape it. I would not believe that my illnesses are spiritually caused and that no one is providing the care for me.

Spiritual Rituals

Regardless of their religion, all 30 participants spoke about spiritual rituals with regard to the care they prefer during their dying process. Two themes emerged regarding spiritual rituals that Christian participants would want: prayer and church involvement. Six themes emerged regarding spiritual rituals that Animist participants would want when they have an illness that could not be cured: shaman rituals done to diagnose illness; shaman rituals done to heal; soul calling; children to arrange and/or perform rituals; psychological adaptation; and integration of Western and Hmong care (see Table 11).

Christian Rituals Regarding Care in the Dying Process. All of the Christian participants (N=15, 50%) talked about Christian rituals that they would want performed if they had an illness that could not be cured. These themes include the ritual of praying and involvement from the church.

Praying. All of the 15 Christian participants talked about the importance of prayers during their dying process. For example, one participant stated, “I think that at that time, I would like prayers to be done. Pray for me. They don't have to sing to me every day. I just want prayers.” Another participant stated, “For Christians, there isn’t anything else besides praying for us.” Nine of the 15 (60%) participants who preferred specific people to pray for them stated that they would like their family members and children to do so. Seven of the 9 (78%) participants spoke about wanting prayers from people at church, including their pastor and other church members. One participant shared, “When we are sick and going to pass away then we must ask

the church to come and pray for us to make sure we will be with God." Another participant said, "Mm, I have told my children that when I have an illness that could not be cured, since I am now a Christian, I would like the pastor to come and pray for me."

Church Involvement. Five of the 15 Christian participants (33%) stated that they would like members from their church to be involved in their EOL care. One participant stated, "…just maybe the priest, some of the elders from the church, visit me, once in a while." Additionally, another participant said that there are specific rituals that they would like people from the church to perform and would like those rituals to be done exactly in the Christian way. They stated:

> I want things to be done exactly as Christians do and no distractions or anything different…The church members would come and sing songs to support you and pray for you. You can join them for a meal, consisting of bread and wine. So you join them for that meal. Even if you can't eat with them, they will join you and eat with you. After that then they will send your body to God.

Animist Rituals Regarding Care in the Dying Process. Fifteen of the 30 (50%) participants (14 who practiced Animism and one who did not practice a religion), spoke about preferring Animist rituals as part of their care for the dying process. Themes emerged from the data included: shaman rituals to diagnose; shaman rituals to heal; children to arrange and/or perform rituals.

Shaman Rituals Done to Diagnose Illness. Four out of the 15 participants (27%) stated that they would like shamanic rituals to be performed in order to diagnose their illness. One participant shared:

> The rituals include doing shaman rituals to see what caused the illness…For shaman rituals, you could contact a shaman who comes and performs a ceremony inside your

> home…If you don't know the reason why someone suddenly falls ill then you would need a shaman to do a ritual to figure out why they are sick…Sometimes the shaman finds out that you have been scared or your soul is wandering, which means that your soul is not with your body and that's why you are sick.

Another participant talked about the importance of doing the shamanic rituals by sharing that it has always been their ancestors' traditional belief. The participant stated, "Our ancestors have always believed in shaman rituals. Plus, if you are sick then you should seek shaman rituals to see if they can find a cure and the reason why you are sick."

Shaman Rituals Done to Heal. Eleven of the 15 participants (73%) talked about performing shaman rituals as a part of their care to attempt to heal them. For example:

> I would like them to do shaman rituals to see if there is anything wrong…and they should do the rituals to make me better…If I am sad or have been scared from other things then they should do shaman rituals to try to cure me so that I feel better…

Soul Calling. Six out of the 15 participants (40%) specifically stated that they would like the soul calling ritual to be done as part of their EOL care. One participant said, "If our soul has left our body and is wandering then we can be sick and possibly die as well. So that's why we have to do these rituals to call our souls back to be with our bodies…"

Children to Arrange and/or Perform Rituals. Four out of the 15 (27%) participants specified that they would want their children to perform the soul calling and shamanic rituals and would expect their children to have them done. One participant stated:

> At that time, I would like my children to do shaman rituals and soul calling for me to see if I would be better…if I am not able to take care of myself then I would like my children

> to do these rituals for me…because I've raised my children to provide care for me during this time.

Participants' Psychological Adaptation. Six of the 15 participants (who spoke of Animist rituals) (40%) stated that they do not expect their children to conduct rituals as part of their care during the dying process.. One participant explained:

> It depends on my children, whether they will do it or not is up to them. If the children say, if they are care and love me and they want to do the rituals to see if they will help, then that is fine. If they don't love and care for me at that time and they don't do any rituals for me, there is nothing I can do. I would not require them to do it at that time…I think of what is right and easy for my children.

Integration of Western and Hmong Care. Three Animist participants (21%) out of the 14, spoke about preferring EOL care that integrates their spiritual rituals with Western healthcare. One participant talked about the role of medical doctors related to Animist rituals. She stated:

> When it comes to being ill and you have sought treatment from medical doctors, and they can no longer cure you then you must go back to your people and believe your traditional beliefs. So when you come back and do your traditional beliefs and rituals and they have tried to cure you and it's not effective then when you go back to the Western doctors, they will be able to see your illness. But if the Western doctors see that your illness is gone then you must come back and believe in the traditional rituals.

Another participant talked about fatalism after seeking both options, especially after seeking medical treatment from Western doctors. The participant stated:

> Shaman rituals should be done first. These are rituals that should be done before going to the doctors. Shaman rituals should be done. Soul calling should be done. If these rituals have been done and the person is still sick then you don't do anymore. You can take them to the doctors but that's it

Summary

This research question sought to gain an understanding of the role that participants' religion, spiritual beliefs, and spiritual rituals played in their EOL care preferences. Half of the participants reported practicing Christianity, 14 reported practicing Animism, and one reported practicing no religion. Christian participants reported their spiritual beliefs with regard to their care preferences including prayers as part of the care and their belief in being responsible for loving and caring for their elders. For Animist participants, spiritual beliefs included belief in spiritual causes of illnesses, belief in doing the rituals to heal or extend life, fate, and in the integration of Western and traditional healthcare. Regarding participants' care preferences related to spiritual rituals, Christian participants said prayer was the only ritual that would prefer and some of these individuals had a preference regarding who did the praying. These participants also preferred members from their church to be involved at EOL and perform Christian rituals. Animist participants reported a myriad of spiritual rituals with regard to their care preferences. They reported that shaman rituals should done to diagnose illness, and then shaman rituals and soul calling should be done to heal illnesses. In regard to who arranges and performs rituals, some participants talked about expecting their children to do so. Furthermore, some Animist participants had psychologically adopted and wanted to integrate Western and Hmong care practices.

CHAPTER 6: DISCUSSION

This qualitative study used the Life Course Theory (Elder, 1998; Elder at al., 2003;), Berry's acculturation typology (1997, 2007) and an intercultural adaptation framework (Searle & Ward; 1990; Ward, 2001) to explore 30 Hmong elder participants' EOL care preferences with regard to their acculturation, adaptation, religion, and spiritual beliefs and rituals. The findings in this study both confirm and extend previous research. Past research on Hmong EOL care has focused on beliefs; encounters with the Western healthcare system that were not culturally sensitive; and did not focus on Hmong elders' EOL care preferences. This study sought to address the dearth of knowledge regarding Hmong elders' care preferences for the dying process by answering five research questions: RQ1: What are Hmong elders' preferences for physical, psychosocial, and culture care during their dying process?; RQ2: What are the differences and similarities of Hmong elders' care preferences for the dying process base on their acculturation strategy?; RQ3: Have Hmong elders made adaptations in their EOL care preferences and if so, what adaptations have they made?; RQ4: What role, if any, do adaptations made by Hmong elders' preferred caregivers play in the elders' care preferences with regard to their dying process?; and RQ5: What role, if any, do Hmong elders' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences for their dying process? Descriptive quantitative analysis and conventional and directed content analysis were used to analyze the data gathered from the interviews. In this chapter, the findings are synthesized and discussed along with limitations of the study and implications for future policy, practice, and research.

Hmong Elder Participants' Preferences for Physical, Psychosocial, and Cultural Care

The first research question explored Hmong elder participants' preferences for physical, psychosocial, and cultural care. The results illustrate the care preferences that were important to

participants and their recognition of the dominant culture's impact on these preferences. The result of this recognition sheds light on the adaptations that these participants have made with regard to their EOL care preferences.

The physical care preferences reported in this study focused on receiving care for ADLs and IADLs and how such care would be provided. While the preference for ADLs, such as bathing, toileting, dressing, and ambulating are common care practices for the physical care domain, the preference for continued food preparation (IADL) that these participants preferred has more of a Hmong cultural influence. Consistent with an earlier study (Culhane-Pera, 2003a), participants felt it was important for elders to continue eating despite their terminal condition, which can be problematic when the body's organs and functions are beginning to shut down. The ingestion of nutrition, particularly artificial nutrition and fluids provides more discomfort to a dying person's body than comfort because of risk for bloating, swelling, and shortness of breath (National Hospice and Palliative Care Organization, 2015). Despite these risks, offering food and fluids to dying family members is viewed in the Hmong culture as an act of love and care towards the dying person and a show of respect for the elder. Respecting the dying elder during their impending death means that the deceased elder will successfully move on to the afterlife and join their ancestors (Gerdner et al., 2007). Not respecting a dying elder will usually anger their spirit and the spirit may come back and cause harm to the elder's living descendants (Vawter & Babbitt, 1997). Furthermore, a respected dying elder will usually impart words of wisdom or some sort of blessings onto the living family members who are present during the elder's last few days (Bliatout, 1993; Culhane-Pera, 2003a). Therefore, the importance of feeding a terminally ill Hmong elder goes beyond love and care and is believed to have a significant impact on their afterlife.

In terms of provision of care, participants were also specific on the details of providing care and who would provide the care. It was important for participants to have caregivers constantly watch over them and be gentle with how they would provide the care to participants. Additionally, modesty also emerged as being crucial to how care should be given. In Her-Xiong & Schroepfer (2018) modesty was also found to be an important caregiving factor for Hmong elders at EOL and participants reported preferring same-sex caregivers. Consistent with Her-Xiong & Schroepfer, participants in this study reported preferring same-sex caregivers and provided gendered caregiving responsibilities if the same-sex caregiver option is not possible. The recurring of modesty and preferring same-sex caregivers in EOL caregiving studies suggest the gravity of these preferences.

It is important to acknowledge that not all participants reported preferring ADLs and IADLs as part of their EOL care preferences; however, this does not suggest that these care options were not important to them. The question in the interview guide in which responses were used to analyze for these themes was open-ended, which provided room for participants to answer the question as they preferred. It could be that ADLs and IADLs are important to these participants, but they chose to not talk about these care options for unknown reasons.

The findings related to psychosocial care preferences for the dying process focused on how the care is to be provided as well as how the participant is to receive that care. Participants spoke about the importance of caregivers speaking gently with them, as not doing so would increase their stress and could make them sicker. They also noted the importance of speaking gently with their caregiver and not shouting at them. Lastly, the care preference of having family and friends present when an elder is dying is consistent with previous literature as collectivistic

caregiving practices have been the dominant approach in the Hmong culture (Culhane-Pera, 2003b).

The cultural preferences with regard to EOL care discussed by participants are consistent with Hmong beliefs regarding care reported in the literature. The two Hmong beliefs regarding EOL caregiving discussed by participants have been reported in other studies: overall provision of care to elders (Culhane-Pera, 2003a; Gervais, 2003; Gerdner, 2008; Her-Xiong & Schroepfer, 2018) and fate (Gerdner et al., 2006). Traditional Hmong believe that surrounding the dying elder is a blessing to their children and those who are present during the elder's death with good fortune (Culhane-Pera, 2003a) and that they will receive good karma in terms of receiving good care from their own children when they are elders and at EOL (Gerdner et al., 2013). The belief regarding fate to guide care during the dying process is supported by previous findings related to "mandate of life" (Gerdner et al., 2006, p. 224). "Mandate of life" is a belief that Hmong have regarding causes of illnesses and suggests that the individual is born with a pre-determined length of time to live (Cha, 2010). When someone suddenly falls ill and remains sick despite all attempts to heal that person, Hmong attribute it to that person's "mandate of life" (Gerdner et al., 2006, p.224). The participants in this study shared that they believed in their fate or "mandate of life" and would not want any kind of care done to extend their lives.

In addition to Hmong beliefs as they relate to EOL care preferences, study participants also discussed Hmong traditions they felt were important for this time in their life with a focus on who provides care and makes care decisions, and a recognition that the Western culture has impacted traditional caregiving practices. In this study, participants shared that it is a tradition for children to provide care to their elders with the elder son and his wife serving as the caregivers. This expectation is based on the belief that the sons inherit and continue their parents' ancestral

and spiritual connections once the parents pass away (Cha, 2003). These connections are necessary in the traditional Animist Hmong culture because of the belief that the ancestor and house spirits protect the home and its inhabitants from negative forces such as illness and harm (Bliatout, 1993; Cha, 2003; Gerdner et al., 2007). In regard to married daughters, however, elders do not live with or receive care from them or their spouses. When a daughter marries, she leaves her own family to become a part of her husband's ancestral family and will receive spiritual protection from his family's ancestors (Culhane-Pera, 2003a; Gerdner et al., 2007). It is for these reasons that traditional Animist Hmong elders want to be under the care of their sons and daughters-in-law.

Hmong elder participants discussed the importance of dying in their own home, their sons' home, or the homes of relatives who have the same last name and traditional beliefs as that of the elder. This practice is especially important for traditional Animist Hmong elders because of the house spirit altar, which is maintained to appease the household spirits responsible for the welfare of the home and its residents (Cha, 2003). Appeasing the spirits may include periodically burning spiritual money and animal, such as chicken or cow, sacrificial (2003).

Lastly, the participants' preferences for the Hmong traditions of caregivers making decisions and collectivistic caregiving connect to the close-kin support system prevalent in the Hmong culture. Participants trusted their preferred adult child caregivers to make the decisions regarding how care should be given. They also spoke to the importance of family and the extended family being present as well as involved in the caregiving. Traditionally, Hmong are organized into a hierarchy of power in which the eldest male has the decision-making authority and consults the clan leader as necessary (Gerdner et al., 2007). Although the eldest male has the authority, decision-making is made collectivistically with the family, relatives, and clan leader as

decision may impact the family as a whole. Hmong who steadfastly practice the cultural traditions maintain strong family ties that are interdependent instead of independent. As a result, family and relatives are present to provide support to the family when a loved one is terminally ill (Culhane-Pera, 2003a).

There are two findings, however, that extend the current Hmong EOL care literature: impact of mainstream culture and preferring a quick death. The first is Hmong elder participants' recognition of the impact of mainstream culture on traditional Hmong caregiving practices. This recognition underscores the importance of collectivistic caregiving and preferring children as caregivers as being the most impacted by the dominant culture in the United States. Participants spoke of realizing that depending on their children to provide care to them is no longer feasible due to lifestyle changes being experienced by adult Hmong children such as working out of the home. As a result, participants spoke about their need to be as independent as possible to avoid having to depend on their children or others for care. This realization also led some participants to forgo traditional care practices and to not expect their children to perform or arrange cultural rituals for them during their dying process. It could also be this realization that led some participants to make psychological and sociocultural adaptations regarding alternative care options. For example, being satisfied with and preferring to live in a care facility during their dying process could be because of their understanding of the Western culture's impact on their traditional care preferences.

The other finding that extends the current literature is the three participants' preference for a quick death. When asked about their care preferences, they spoke of not wanting to need care or to have people care for them. This finding contradicts the Hmong belief that one must exhaust all treatment options in order to cure the terminally ill person (Vawter & Babbitt, 1997).

Participants did not provide additional information regarding their preference and so it is hard to know if this is an adaptation to the realization that some traditional Hmong caregiving practices may no longer be feasible. This preference for death is an area requiring more study.

Differences and Similarities of Hmong Elder Participants' Care Preferences for the Dying Process Based on Their Acculturation Strategy

As stated earlier, this study did not aim to test Berry's acculturation typology (1997) and Ward's intercultural adaptation framework (2001); rather, these frameworks served as guidance to exploring participants' acculturation strategies and adaptations. As evidenced in the results section, some participants were using one acculturation strategy (separation and integration) and others two (separation & integration and integration & assimilation), which differs with previous researchers who used Berry's acculturation typology and found participants to be using one acculturation strategy. The use of two acculturation strategies could be due to this study capturing participants at a time when they were moving from one strategy to another, or that participants utilized different acculturation strategies depending on the situation. This is an area in need of future study.

The reported participants' care preferences were compared based on their acculturation strategies leading to some interesting findings. Compared to the other acculturation strategies practiced by participants, those practicing the separation strategy had a greater preference for traditional Hmong caregiving practices such as having children provide care for elders, dying at home, and collectivistic caregiving, a finding similar to Lee and Green's (2010). A majority of the integration participants in this study preferred traditional Hmong caregiving practices but also recognized that they may not receive them due to the impact of the Western culture. These

participants' preferences align with their integration acculturation strategy and are also consistent with the current literature (Lee and Green, 2010).

While there are no studies that have found participants practicing more than one acculturation strategy, participants in the current study were found to do so. In regard to participants using both separation and integration, their preferences for Hmong caregiving traditions are similar to those practicing only separation and only integration. Similar to participants practicing integration, the separation & integration participants spoke about their recognition of the dominant culture's impact and their need to adapt as a result. These participants were seeking to maintain their traditional culture, while also working to adapt to their host culture. It is interesting to note the response to the care preferences reported by the single participant practicing both integration and assimilation. This individual did not report physical or psychosocial care preferences; rather, they reported only preferences for traditional Hmong caregiving practices, and discussed their awareness of the Western culture impact on the likelihood that they may not receive their care preferences. They expressed the need for them to remain as independent as possible and not expect their children to perform or arrange for any cultural care rituals for them. They also noted a preference for a quick death, although it was not clear if this was related to the possibility that their care preferences would not be honored. This participant demonstrated similarities with the integration participants, who also reported a preference for Hmong traditional caregiving practices and understood they might not receive their preferences due to the impact of Western culture. While this finding is limited to one participant, the participant's acculturation characteristics are consistent with the assimilated participants in Lee and Green's (2010) study and with Berry' (1997, 2005, 2015), who demonstrated comfort and preference for interaction with their host environment. These findings

provide evidence of the role that acculturation may place in regard to the EOL care preferences of Hmong elders.

Hmong Elder Participants' Adaptations in their EOL Care Preferences

Results from this research question suggest that participants were making adaptations with regard to their EOL care preferences in response to their preferred adult child caregivers' adaptations as a result of living in the United States. About two-thirds of the participants have made adaptations with regard to their EOL care preferences and one-third reported to have not made any adaptations. The adaptations participants made were related to psychological and sociocultural adaptations posed by the intercultural adaptation framework (Ward, 2001). While psychological adaptations refer to one's satisfaction and overall emotional well-being, sociocultural adaptation is that of the person's behavior and sociocultural skills they gain in order to live effectively in their host society (Searle & Ward, 1990; Ward, 2001).

Participants talked about two psychological adaptations they had made regarding the EOL care they preferred and what they likely would be receiving from their adult children, who were their preferred caregivers: satisfaction with and acceptance of EOL care provided to them and understanding and supportive of their adult children's need to work. The adaption with regard to participants' understanding and supporting children's need to work relates to the fact that Hmong are now living a lifestyle very different from how they were when they lived in their home country. In their home country, Hmong families lived near each other and worked on the same farm or nearby farms so aging elders and those who were sick could be taken care of by their children, but such is not the case in the United States (Gerdner, 2008). The lifestyle in their new host country has proven challenging to Hmong families and has necessitated adult Hmong children to make sociocultural adaptations with regard to the type and location of work available

to them in the United States. Work requirements have led to adult children's having to relocate and, working full-time outside of the home thus preventing adult Hmong children from continuing to provide full-time care to their aging and terminally ill elders. Participants reported being understanding and supportive of their children's need to make this sociocultural adaptation. In doing so, they have made the psychological adaptation of being satisfied with and accepting of the EOL care their children will be able to provide.

The psychological adaptations reported by participants appear to have led participants to make their own sociocultural adaptations. These adaptations relate to care options that participants would like to receive in lieu of their children providing care for them: use of healthcare technology, Western healthcare options, care facilities, and any type of care available. The adaptations made by these participants can be understood through the frame of the Life Course Theory (Elder et al., 2003). One principle of this theory is that of linked lives, which suggests that the work-related sociocultural adaptations Hmong children have made since living in the United States have had an impact on participants' care preferences to the point of their being open to using mainstream care options. The finding that several participants were open to and accepting of living in care facilities or receiving care from formal caregivers is profound because it is a shift away from traditional Hmong caregiving practices. Furthermore, the human agency principle (Elder et al., 2003) can be seen in participants having the agency to make decisions based on the opportunities and limitations in their environment. Participants' decision to be open to other care options can be explained by the limitation of their children not being able to provide care to them. This adaptation can also be explained by the principle of human development as a lifelong process (Elder et al., 2003), specifically elders' adaptations for care

preferences because they continue to develop and grow by learning and adjusting to the lifestyle in the United States.

Participants who did not make adaptations shared that they would still want the Hmong traditional practices with regard to caregiving, which is consistent with previous literature (Culhane-Pera, 2003a; Gerdner, 2008). They would still want their children to provide care to them regardless of the country in which they live. Although these participants would prefer the same care despite the country they live in, it is interesting that some recognized the caregiving services and support available to their children in this country. Participants who preferred the same care were those practicing separation, integration, and those who were practicing both separation and integration at the same time. It is important to note that future research is necessary in order to gain a deeper understanding regarding whether participants who felt they could still receive their preferred traditional care preferences was due to the availability of these mainstream caregiver services and support.

Hmong Elder Participants' Preferred Caregivers' Adaptations

The fourth research question sought to understand the impact that adaptations made by caregivers had on participants' beliefs regarding whether they would receive their preferred care and whether their preferred caregivers would actually provide this care. It is interesting to note that some participants did not know if they would receive their preferred care, some did not believe they would and some did believe so.

With regard to participants who did not know whether they would receive their preferred care two key themes emerged from their responses. Some of these participants reported that they had no care expectations and some were unsure whether their preferred adult child caregivers will care about them enough to provide care to them. The impact on the participants of the

sociocultural adaptations made by their children is an important one to consider. For these participants to have no care expectations or doubt their children would care about them is at odds with the traditional approach to EOL care that notes certain ways to not disrespect the terminally ill elder such that the spirit of the deceased loved one will feel respected and not trouble the family members in the future (Vawter & Babbitt, 1997).

The impact of their children's sociocultural adaptions is also evidence for those who do not believe they will receive their preferred care. Some participants reported that their children were exhibiting behaviors that showed a lack of care or an uncertainty of care towards them and others spoke about the role that their preferred caregiver's sociocultural adaptations might have. It is important to look at these themes through the lens of intercultural adaptations and the demands of working in the United States (Gerdner et al., 2008) because it could be that these adult children have adapted to the Western culture and the results have resulted in it being difficult for them to show care to their parents in a way they would understand.

The impact of participants' preferred adult child caregivers' adaptations for participants who do not know and do not think that caregivers will provide care to them is important to consider. Participants felt that not only were their children making adaptations with regard to employment, the adaptations were "American." They felt that their children had adapted to the extent of foregoing Hmong traditions and becoming more "Americanized." This finding is similar to what is currently known in the literature in which Hmong elders and their children utilize different acculturation strategies.

Participants who reported believing they will receive their preferred care felt that it was because they believed their preferred adult child caregivers' adaptations were having no effect on them and they (participants) did not expect any kind of care from their children (psychological

adaptation). It is interesting to note that despite living in a new environment and lifestyle, some participants still reported a preference for traditional Hmong caregiving practices and their children as their caregivers. On the other hand, some participants felt they would receive their preferred care because they would be satisfied with any kind of care whether it be from their children or caregivers at the care facilities. This attitude of being satisfied with any kind of care is a form of psychological adaptation (Searle & Ward, 1990; Ward, 2001).

Psychological adaptations were reported by all participants who did not know, did not think, or did think that their preferred caregivers would provide the care they preferred. While this theme emerged for participants in all three response categories, the reasons given differed based on their psychological adaptation. For those who did not know, they empathized with their adult child caregivers because they (participant) could not be a caregiver to their own spouse. Furthermore, they had already accepted that their children would likely not be their caregiver. In regard to the participants who did not think their preferred caregivers would provide care to them, they were understanding that they would not have any control over the care they would receive and, in believing so, would be accepting of any kind of care. Lastly, the participants who did believe that their preferred caregivers would provide care to them believed so because they were open to receiving any kind of care from any caregivers whether they were adult children or caregivers at the care facility. All of these reasons are further evidence of the psychological adaptations made by the participants.

Another way to gain an understanding of the impact of caregivers' adaptations on participants' care preferences is to compare who the participants prefer to provide their care and who they would choose as an alternative if their preferred caregiver was unavailable to assume the role. When examining their preferred caregivers, it was not surprising that participants

practicing separation all preferred their children while participants practicing integration preferred a variety of caregivers. The separated participants' preferences for their adult children as caregivers is consistent with the characteristic of separation as wanting to maintain one's primary cultural practices (Berry, 1997, 2005, 2015; Sam & Berry, 2010). Similarly, Berry's definition of integration provides guidance to understanding those participants preferring a variety of caregivers including their adult children and care facilities. Participants who were practicing both acculturation strategies of separation and integration preferred their children, spouse, care facility as well as having no preferences. The one participant practicing both integration and assimilation acculturation strategies preferred their children as caregivers. The preferred caregiver findings of these two groups of participants who were practicing two acculturation strategies are consistent with the characteristics of separation in preferring their traditional cultural practices, integration in preferring both primary and host culture, and assimilation in preferring mainstream culture (Berry, 1997, 2005, 2015; Sam & Berry, 2010). When given the opportunity to think about alternative caregivers should their preferred adult child caregivers not be able to provide care, participants reported alternative caregivers such as formal, informal, and care facility, while others reported not knowing and would prefer death over not having their children as caregivers. It is interesting that some participants reported informal caregiver such as their relatives or other family members as alternative caregivers while others reported more mainstream options. These differences provide more understanding of the diversity of participants' care preferences.

Hmong Elder Participants' Care Preferences with Regard to Their Religion, Spiritual Beliefs, and Spiritual Rituals

In regard to the fifth research question about the role that Hmong elder participants' religion, spiritual beliefs, and spiritual rituals play with regard to their care preferences, interesting findings emerged. In terms of religious practices, half of the participants in this study were Christians, while 14 were practicing Animism and one did not practice any religions. This current study provided an almost equal representation of the major religions practiced in the Hmong community, which is different from the religious representation in previous studies wherein more Animist participants were recruited (Gerdner, 2012; Gerdner et al., 2008; Her-Xiong & Schroepfer, 2018).

The spiritual beliefs and rituals that Christian participants have with regard to prayers at EOL is consistent with previous studies (Culhane-Pera, 2003a; Her-Xiong & Schroepfer, 2018). Including prayers as a spiritual belief was important for participants because they believed in praying to God and for His guidance. Similarly, the belief in prayers was reported as providing comfort for reducing the stress of someone who is terminally ill or in making those individuals happy. The person who did the praying was important for participants, whether it was their family, children, or members of their church and pastor. The knowledge that not all Hmong practice their traditional religion of Animism is important for healthcare providers to understand the heterogeneity of the Hmong community.

The Animist spiritual beliefs and rituals found in this study are consistent with the current literature (Cha, 2003; Culhane-era & Xiong, 2003; Her-Xiong & Schroepfer, 2018). The belief in spiritual causes of illnesses provides guidance to understanding the rituals that are performed when a loved one is terminally ill. It is impossible to discuss spiritual cause of illness without

discussing shaman rituals for healing and soul calling. These beliefs and rituals are interwoven into Hmong beliefs and practices regarding illnesses (Johnson, 2002; Lee & Pfeifer, 2006). For example, a shaman ritual would be done to diagnose the illness and spiritual treatments such as soul calling or a healing ritual would be recommended by a shaman in attempt to cure the person of the sickness.

The findings regarding some participants' integration of Western and Hmong spiritual beliefs and rituals must be acknowledged as they are consistent with the current literature. Previous literature consist of case studies and findings that provide support to traditional Hmong's use of Animist spiritual beliefs and rituals with their use of Western healthcare services (Culhane-Pera, 2003a; Culhane et al., 2003; Neiman, 2019).

The principle of diversity in life course trajectories (Elder et al., 2003; Shanahan, 2000). can provide guidance to understanding participants' care preferences as they relate to their religion, spiritual beliefs, and rituals. This principle provides that people's life course trajectories differ base on factors such as age, gender, religion, beliefs, locations, among others (Shanahan, 2000). The principle guides the understanding of participants practicing different religions with some converting to Christianity after immigrating to the United States. Furthermore, this principle provides guidance to understanding the diversity of participants' future dying trajectories with care preferences related to their religion, spiritual beliefs, and rituals.

Study Findings and Theoretical Framework

The findings in this study generally support using the Life Course Theory to understand Hmong elder participants' care preferences for the dying process with regard to acculturation strategies, intercultural adaptation, religion, spiritual beliefs, and spiritual rituals. The principle of human development as a lifelong process states that people continue to develop beyond

adolescent years (Elder, 1998; Elder at al., 2003). This principle provided guidance to understanding how Hmong elder participants and their children acculturated and adapted after immigrating to the United States. The principle of human agency states that human beings create their own life course through the choices they make with regard to the constraints and opportunities in their environment (Elder, 1998; Elder at al., 2003). This principle guided the understanding of how participants acculturated in their new environment and the resulting adaptations had implications for their care preferences as was evident in the results section. The principle of time and place and timing in lives provided guidance to understanding participants and their adult children's adaptations. For these elder participants, who came to the United States rich in their traditions due to the length of time spent in their home country, the adaptations they made were more in response to the younger generations' (children) adaptations. These children, who had spent less time in their home country and not as tied to traditions have had to acculturate and make adaptations differently than their elders because they were young enough to work and interact more with the U.S. economy and culture. The difference in timing of immigration suggested that participants' and their children's immigrating to the United States resulted in different experiences for them, which impacted how they adjusted to living in the United States. The principle of linked lives provided understanding regarding how participants and their preferred caregivers' (adult children) lives are interdependent and how the changes in one's life impact another's life as was seen in this study. The principle of diversity in life course trajectories (Elder, 1998; Hutchison, 2010) also provided guidance to understanding the diversity of participants' care preference trajectories, particularly with regard to their differing religion, spiritual beliefs, and spiritual rituals. This principle guided the understanding that participants' care trajectories were found to differ based on generations (elders and their adult children).

Not only did the principles of the Life Course Theory frame this study, its concepts also provided context to the adaptations participants and their preferred caregivers made. The transition concept is that of small changes in status or departures from previous roles (Elder, 1998; Elder at al., 2003). The transition most noted in this study was that of participants' children leaving their family's home and starting careers. This concept also provided guidance to understanding the acculturation strategies that participants made as they transitioned throughout their life courses in the United States. In this study, participants were asked to consider the trajectory of their dying process for the future and their reported care preferences are part of their trajectories. The turning point (Elder, 1998; Elder at al., 2003) that is of most noteworthy in this study was that of participants immigrating to the United States. This abrupt and substantial change in direction of their lives impacted their living arrangements, lifestyle, and subsequently their caregiving practices.

Acculturation Typology and Intercultural Adaptation

Berry's acculturation typology (Berry, 1997, 2005, 2015; Sam & Berry, 2010) and Ward's intercultural adaptation framework (2001) guided the directed content analysis for this study. The findings suggest that the acculturation typology support its application for understanding participants' acculturation strategies with some modifications. While some participants were using one acculturation strategy, others were using two, which has not been the case for previous studies that have used this typology.

The intercultural adaptation framework (Ward, 2001) provided understanding of the adaptations made by the participants and their preferred caregivers. This study provides evidence regarding the need for researchers and healthcare professionals to take into account the role psychological and sociocultural adaptations play in caregiving. The use of this framework sheds

light on understanding the types of adaptations that participants reported and their impact on care preferences for the dying process. It also provided knowledge regarding participants' preferred caregivers' adaptations as a result of living a different lifestyle in the United States, and provided insight into how their adaptations have impacted the participants' EOL care preferences.

IMPLICATIONS FOR SOCIAL WORK PRACTICE, POLICY, AND RESEARCH

Implications for Social Work Practice and Policy

Knowledge gained from understanding Hmong elder participants' care preferences during the dying process has important implications for the field of social work. As social work practitioners, the principles of our profession compel us to honor the dignity and worth of the person, challenge social injustice, and promote the field's development (National Association of Social Workers, 2017). Social workers serve as advocates for patients in the healthcare setting and function to ensure that patients receive culturally sensitive care. One way for social workers to advocate is that of being gentle and understanding with approaching Hmong families regarding the concept of continued feeding loved ones who are terminally ill. Social workers should provide education to families about the risks of continued feeding while still being respectful of the families' decisions to do so. Another implication is that of social workers using culturally sensitive assessments. Questions that will allow the social worker to learn more about the elders in terms of their acculturation, adaptations, religion, spiritual beliefs, and rituals should be considered. Furthermore, these assessments should include questions that allow the social worker to also learn about the elders' family and children's adaptations so they could better facilitate conversations with elders and their families as well as advocate for the elders' needs. For medical social workers, understanding Hmong elders' EOL care preferences can assist them in ensuring that these elders experience a quality dying process. By having knowledge of these

EOL care beliefs and practices, and the heterogeneity within the Hmong community as a result of acculturation, adaptation, religion and spiritual beliefs, social workers may be better equipped to advocate for care that is in line with Hmong elders' culture and preferences.

Another practice implication relates to culturally sensitive hospice care services. The hospice care philosophy shapes hospice social workers' roles. This philosophy states that support and care provided to dying patients and their family members must be holistic and focus on the individual's psychosocial, spiritual, and cultural needs at EOL (NHPCO, 2015; Reese, 2013). For hospice social workers, having a deeper understanding of Hmong history and their immigration to the United States, as well as knowledge of their cultural values, beliefs and traditions surrounding EOL, will assist them in the provision of culturally appropriate hospice care and services to Hmong elders and their families.

Hospice care agencies should consider a review of their trainings to determine if they are culturally sensitive, and if not, to develop policies that require all administrators, leaders, and frontline staff to receive consistent experiential learning opportunities about providing culturally sensitive care to minority patients. Additionally, administrators, leaders, and frontline professionals should be proactive instead of reactive with regard to obtaining learning opportunities to provide care to patients from diverse cultures.

This study provides evidence that supports the implementation of policies to promote culturally sensitive care and services for Hmong and other refugees and immigrant communities. Social workers' understanding of Hmong elders' EOL care preferences may support their increasing awareness that similar knowledge and services are necessary for other refugee and immigrant communities as the United States is the leading country in the world with the greatest number of immigrants at 44.7 million in 2018 (Batalova, Blizzard, & Bolter, 2020). The number

of immigrants accounted for 13.7% of the U.S. population in 2018. By 2065, immigrants and their descendants are projected to make up 88% of the U.S. population (Radford, 2019). Since the Refugee Resettlement Program in 1980, approximately three million refugees have resettled in the United States, making the country the top in this category as well. The increasing number of refugees (U.S. Department of State, n.d.) and immigrants (Baker, 2016; Zong & Batalova, 2017) coming to the United States serves as an impetus for social workers to be active in promoting culturally sensitive EOL care. States and federal government should enact policies that provide support to agencies and its personnel regarding providing culturally sensitive care to different communities. Policies mandating training for healthcare professionals and other providers regarding the risks, safety, and appropriate services to this population are also necessary.

Implications for Social Work Research

A number of implications for social work research emerged in this study. Further research should be conducted to include interviews with Hmong adult children who are most likely the caregivers to their elders regarding their perspectives of the Hmong caregiving structure, their acculturation strategies used, and resulting intercultural adaptations. Research should be conducted to gain a better understanding of these adult children's lives in the United States, how their lives are inter-linked with their elders, and the next steps to caregiving for Hmong elders at EOL. Adult children's acculturation is important to examine because researchers found that Hmong children were more acculturated compared to their parents (Rick & Forward, 1992). Researchers (Lee & Green, 2010) have also cautioned that the Hmong will continue to acculturate and move towards assimilating into the dominant culture. They predict that eventually, members will lose knowledge of their culture and language, and a large subgroup

of the community will become “marginalized” (Lee & Green, 2010, p. 17). If this becomes the case, care preferences and the potential for Hmong children and family members to provide care are likely to be impacted, thus necessitating further research.

Participants’ use of two acculturation strategies is an area that needs further study. The use of two acculturation strategies needs further understanding because it is unclear why participants were doing so in this study. Future research should consider methodological approaches that are culturally sensitive but provides deeper investigating of Hmong elders’ acculturation strategies.

The finding that some participants reported preferring a quick death warrants further investigation. Further research is necessary to understand whether preferring a quick death has any implications on Hmong elders’ EOL care preferences. The fact that two participants who were practicing separation reported preferring a quick death over not receiving the care they would like to receive is interesting. The correlation between preferring a quick death and participants’ acculturation strategies and intercultural adaptations is unknown and should be further researched.

Another research implication focuses on understanding Hmong elders who integrate Western and Hmong traditional caregiving beliefs and rituals. Further research could provide understanding to participants who feel that they could still receive their traditional care preferences because of mainstream resources available to support their adult child caregivers. It may be necessary to study Hmong elders whose religion differs from their spiritual beliefs and rituals. For example, Gerdner (2012) found that a Hmong Christian elder held beliefs that health problems are spiritually caused but prayed to God for healing. Such research has the potential to

provide further understanding in providing care to Hmong elder patients who wish to integrate the dominant culture's healthcare services within their primary cultural beliefs and practices.

Lastly, it is important that researchers use culturally sensitive approaches when conducting research with different communities. When researchers study sensitive topics or cultures, they should involve elders, leaders, or other important people from within the community to ensure cultural accuracy, sensitivity, and language access. The use of snowball and purposive sampling methods were effective in this study as they allowed for trust to be built between the researcher and the potential participants.

METHODOLOGICAL LIMITATIONS

Several limitations are inherent to the study. First, this study was cross-sectional and exploratory, so it did not capture the longitudinal perspective as suggested by the Life Course Theory (Elder, 1998; Giele & Elder, 1998; 2009). Second, only one participant was using the integration & assimilation acculturation strategy combination so this limitation should be taken into consideration when reading the results related to this participant's care preferences. Third interviews were not conducted with the participants' preferred caregivers and so only the participants' perspectives on intercultural adaptations and their adult children's ability to provide care were studied. Fourth, the sampling strategy selected participants from a certain geographical location and is not representative of the care preferences of all Hmong elders living in the United States. Although I attempted to recruit a diverse sample of Hmong elders from two states in the Midwest, the majority of participants came from urban cities in only one state. Fifth, sampling bias was likely to have occurred as the topic was a sensitive one in the Hmong culture and so the choice to participate might have been motivated by the participant's openness to the topic. Sixth, having another person in the room when the participant was answering the interview questions

may have influenced them to provide answers that were more socially acceptable. Finally, my identity and background as a Hmong person immersed in the Hmong and mainstream culture, may have influenced how I interpreted the data.

CONCLUSION

This study sought to understand Hmong elder participants' care preferences for the dying process with regard to their acculturation strategies, intercultural adaptations, religion, spiritual beliefs, and spiritual rituals. The Life Course Theory (Elder, 1998; Elder et al., 2003) provided guidance to the design of the study and creation of interview questions. Conventional and directed content analyses were used to analyze the data; Berry's acculturation typology (1997, 2005, 2015) and Ward's intercultural adaptation framework (2001) guided the directed content analysis method. This study insured cultural sensitivity toward the participants by involving experienced researchers and Hmong elders during the interview guide development and recruitment phase. The 30 participants provided information useful for garnering an understanding of the care preferences they would like to receive during their dying process. Participants were practicing different acculturation strategies including: separation, separation & integration, integration, and integration & assimilation. Participants also reported a myriad of care preferences with regard to their dying process. Knowledge was gained regarding Hmong elder participants' adaptations related to their EOL care preferences and their preferred adult child caregivers' adaptations. The impact of these adult children's adaptations led to participants making some psychological and sociocultural adaptations with regard to the care they would like to receive. Findings from this study can contribute to building a body of knowledge about providing culturally sensitive care to Hmong elders at EOL and offer implications for social work practice, policy, and research. More importantly, this research sheds light on the

heterogeneity of Hmong elder participants' experiences, acculturation, intercultural adaptation, and EOL care preferences.

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APPENDIX A

Flyer in English

Are you a Hmong Elder?

Hi! My name is Youhung Her-Xiong and I am a UW-Madison Graduate Student

- **I would like to talk with Hmong elders who are 60 years of age or older, and have at least one child living in the US**
- **I want to learn from you about caring for a Hmong person**
- **We would talk about 30 minutes**
- **You will receive a $25 gift card as a thank you**

If you are interested or have questions, please contact me by phone (**608-571-2580**) or email (yher2@wisc.edu)

APPENDIX B

Flyer in Hmong

Koj puas yog ib tug laus?

Nyob zoo! Kuv lub npe hu ua Youhung Her-Xiong kuv yog ib tug ntxhais kawm ntawv qib siab hauv lub tsev kawm ntawv UW-Madison

- **Kuv xav tham nrog cov laus uas muaj hnub nyoog 60 xyoo rov sauv, thiab muaj tsawg kawg ib tug menyuam nyob rau teb chaws Ameliskas no.**
- **Kuv xav kawm los ntawm koj txog Hmoob txoj kev pab cuam thiab tu ib tug neeg laus uas yog Hmoob**
- **Wb yuav siv sij hawm li 30 feeb los sib tham**
- **Kuv yuav muab ib daim npav khoom plig (gift card) uas muaj 25 duas las los ua tsaug rau koj**

Yog koj xav qhia txog Hmoob txoj kev tu neeg laus los yog muaj lus nug, thov hu rau kuv ntawm tus xov tooj (**608-571-2580**) los email (yher2@wisc.edu)

APPENDIX C

Letter of Introduction in English

Letter of Introduction

Date:

Hello! My name is Youhung Her-Xiong and I am a student in Social Work at the University of Wisconsin- Madison. I am doing a study that involves talking to Hmong elders such as yourself. I would like to understand the care that Hmong elders would give to another individual and what kind of care they would like for themselves for the time when they have an illness that could not be cured. The results from this study will be used to understand how good care can be provided to Hmong elders.

I would like to interview Hmong elders who are 60 years or older, born in Southeast Asia and came to the U.S., speak Hmong and/or English, and have at least one adult child living in the U.S. If you would like to participate in my study, I will set up a time to meet and talk with you. The interview will be done at a place and time that works best for you and will last about 30 minutes. ***To thank you for your time, I will give you a $25 gift card at the end of the interview***.

Everything you share with me will be kept confidential; that is, your name will not be written on anything so that no one will know who gave me this information. Your participation is voluntary, and you can stop the interview at any point. If you do not want to answer any questions, you can say no. Participating or not participating in this study or stopping participation will not affect any services you may be receiving from any agencies.

If you would like to participate, please have the agency staff contact me. You can also contact me by phone at (608) 571-2580 or by email at yher2@wisc.edu.

Sincerely,

Youhung Her-Xiong, MSW, APSW
Doctoral Candidate

APPENDIX D

Letter of Introduction in Hmong

Daim Ntawv Qhia Txog Tus Tshawb Fawb thiab Txoj Kev Tshawb Fawb

Hnub:

Nyob zoo! Kuv lub npe hu uas Youhung Her-Xiong kuv yog ib tug ntxhais kawm Social Work nyob rau huav lub tsev kawm ntawv University of Wisconsin-Madison. Kuv xav kawm txog Hmoob txoj kev uas pab cuam rau tu neeg laus thiab tu neeg uas muaj ib tug mob kho tsis zoo. Kuv xav nrog cov laus li koj tham. Txoj kev uas yuav tshawb fawb no yuav qhia tau hais tias tu ib tug neeg Hmob uas yog ib tug laus zoo li cas tiaj li zoo.

Kuv xav kawm los ntawm cov laus uas muaj hnub nyoog 60 xyoo rov sauv, uas yug tim ub es tuaj nyob rau teb chaws Amelikas no, hais lus Hmoob los lus Askiv, thiab muaj tswag kawg ib tug menyuam nyob rau teb chaws Amelikas no. Yog tias koj tsis xav li cas kuv xav kawm los ntawm koj txog txoj kev tu neeg. Kuv mam li teem sij hawm tuaj ntsib koj thiab nrog koj tham. Wb yuav siv sij hawm li 30 feeb los tham. Tsis muaj dab tsi ua tsaug rau koj tab sis tsuas muaj ib daim npav khoom plig (gift card) uas muaj 25 duas las ua tsaug rau qhov uas koj siv sij hawm los nrog kuv tham.

Yuav tsis pub leej twg paub hais tias koj nrog kuv tham txog qhov ntawm no. Kuv tsuas yog siv tej yam uas koj qhia kuv xwb kuv yuav tsis siv koj lub npe. Tsuas yog koj txaus siab tham xwb, yuav tsis yuam koj. Yog hais tias koj pib nrog kuv tham tab sis koj ho pauv siab tsis xav tham lawm los tsis ua cas. Koj yeej tsum lo tau. Tsis tas li ntawv, yog muaj tej nqi lus us kuv noog koj es koj tsis xav teb los tsis ua cas. Kuv yeej tsis yuam koj thiab. Qhov uas koj koom nrog kuv tham no yuav tsis muaj kev cuam tshuam rau tej kev pab cuam uas koj tau txais los ntawm lwm cov tsev koom hauv pab neeg.

Yog koj xav thiab txaus siab tham txog txoj kev pab cuam no, tus neeg ua hau lwm hauv lub tsev koos haum mam li hu tuaj qhia rau kuv. Yog koj muaj lus noog dab tsi koj hu rau kuv ntawm tus xov tooj no los tau (608) 571-2580 los sis xa email tuaj rau kuv ntawm yher2@wisc.edu.

Ua tsaug,

Youhung Her-Xiong, MSW, APSW
Tus Ntxhais Kawm Ntawv Qib Siab

APPENDIX E

Consent Form in English

UNIVERSITY OF WISCONSIN-MADISON
Research Participant Information and Consent Form

Title of the Study: Hmong Elders' Care Preferences for a Time When They Have an Illness that Could Not Be Cured
Principal Investigator: Tracy Schroepfer (phone:(608)-263-3837 email:(tschroepfer@wisc.edu))
Student Researcher: Youhung Her-Xiong (phone: (608) 571-2580 email:(yher2@wisc.edu))

WHAT IS THE RESEARCH STUDY ABOUT?
The purpose of this study is to learn from Hmong elders about the physical, emotional, social, and cultural care they would like if they have an illness that could not be cured. I would like to learn about whether the care you would have wanted to receive in your homeland has changed since living in the US, as well as who provides that care. I also hope to learn about your religious and spiritual beliefs.

WHAT WILL MY PARTICIPATION INVOLVE?
If you would like to talk with me, I will meet with you in person at a place and time that you want and talk for about 30 minutes. When we talk, I will ask you 23 questions and will read each question to you. Your answers will be audio-recorded. If you choose to not be audio-recorded, I will write down your answers. If I meet you in your home, I may have to report any abuse or neglect that I see e. Please know that your decision about whether to talk with me will not affect the services you may receive from any agencies.

ARE THERE ANY RISKS TO ME?
When you are answering the questions, you may feel uneasy about some of them. If you feel this way, we can skip those questions and move on to the next one. You may also feel like you do not know the answer to a question but there is no right or wrong answer.

ARE THERE ANY BENEFITS TO ME?
You may not benefit directly from this study, but the information you share will help doctors, nurses, social workers and others who want to provide good care to Hmong people. You will also receive a $25 gift card for talking with me.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?
There might be publications from this study, but your name will not be used, and all results will be combined. The interview guide, consent forms, and audiotapes will not be shared with anyone and will be locked in a cabinet at our research office, which only I will be able to open. The interview guides will be destroyed in two years and the consent forms in seven years. The audio-recordings will be deleted after the study is finished.

If you choose to be part of this study, I would like to use your exact words without using your name. If you agree to allow me to use your exact words in publications, please initial the statement at the bottom of this form.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask questions about the study at any time. If you have questions after talking today, you can contact the Principal Investigator Tracy Schroepfer at (608) 263-3837. You may also contact the student researcher, Youhung Her-Xiong at (608) 571-2580.

If you are not happy with the answers you receive, have more questions or want to talk with someone about your rights as a research participant, you should contact the Education Research and Social & Behavioral Science IRB Office at 608-263-2320.

Your participation is completely voluntary.

Signing this form means you have read it or I read it to you, been able to ask any questions you have about taking part in this research and that you voluntarily agreed to talk with me. You will receive a copy of this form to keep.

Name of Participant (please print): _____

_____

Signature Date

_____ I agree to have my interview audio-taped.

_____ I give my permission to be quoted directly in publications without using my name.

APPENDIX F

Consent Form in Hmong

LUB TSEV KAWM NTAWV UNIVERSITY WISCONSIN-MADISON
Daim Ntawv Tso Cai Ntawm Tus Neeg Koom Tes Rau Kev Tshawb Fawb

Lub Npe Ntawm Txoj Kev Tshawb Fawb: Kev Pab Cuam Thiab Tu Cov Laus Rau Lub Sij Hawm Uas Muaj Mob Kho Tsis Zoo
Tus Thawj Coj Ntawm Txoj Kev Tshawb Fawb: Tracy Schroepfer (xov tooj: (608) 263-3837) (email: tschroepfer@wisc.edu)
Tus Ntxhais Kawm Ntawv Pab Tshwab Fawb: Youhung Hawj-Xyooj (xov tooj: (608) 571-2580) (e-mail: yher2@wisc.edu)

TXOJ KEV TSHAWB FAWB NO YOG DAB TSI?
Txoj kev tshawb fawb no yog nhriav kev pab cuam thiab kawm txog txoj kev uas yuav tu ib tug laus uas muaj mob kho tsis zoo. Kuv xav kawm txog cov laus tej kev ntshaw thiab kev pab cuam txog yuav tu lawv li cas, kev txhawb lawv dej siab dej ntsws, thiab tej yam uas Hmoob ib txwm ua thaum lawv tu ib tug neeg mob kho tsis zoo. Kuv xav kawm txog qhov uas cov laus yoog los sis hloov Hmoob ke li kev cai txog tej kev pab cuam thiab kev tu neeg seb ho txawv li cas txij thaum lawv tuaj nyob rau teb chaws no. Tsis tas li ntawv, kuv kuj xav kawm txog cov laus tej kev ntsheeg thiab kev cai dab qhuas thiab.

QHOV KUV KOOM TES ZOO LI CAS?
Yog koj tso cai thiab xav nrog kuv tham txog qhov no, kuv mam li tuaj ntsib koj ntawm ib qho chaw uas koj xaiv thaib thaum ib lub sij hawm uas zoo rau koj. Qhov uas wb sib tham yuav siv sij hawm li 30 feeb. Kuv muaj 23 nqi lus yuav noog koj thiab kuv mam li maj mam noog ib lo zuj zus rau koj. Yog koj tsis xav li cas no kuv yuav muab koj cov lus kaw khaws tseg es thiaj li tau muab los sau tseg. Yog tias koj tsis xav kom muab koj cov lus kaw cia los tsis ua cas, kuv mam li sau koj cov lus rau ib daim ntawv. Yog koj xav kom kuv tuaj ntsib koj hauv tsev los tau tab sis tuas yog muaj ib qho hais tias yog kuv pom tej kev tsim txom neeg hauv koj lub tsev, nom tswv muaj txoj cai tuav kuv kom kuv yuav tsum hu qhia nom tswv. Qhov uas koj tham qhia txog tej kev pab cuam thiab tu neeg no yuav tsis muaj kev cuam tshuam rau tej kev pab cuam uas koj tau txais los ntawm cov tsev koom hauv pab neeg.

PUAS MUAJ KEV TXHAWJ XEEB?
Tej zaum yuav muaj qee nqi lus noog uas koj yuav tsis paub teb. Tabsis kuv yuav tsis yuam kom koj teb kom tau. Tsis tag li ntawd xwb, txhua nqi lus uas koj teb yuav tsis muaj hais tias yog los tsis yog. Tsuas yog xav nrog koj sib tham kom tau taub txog koj txoj kev xav xwb. Yog muaj tej nqi lus uas koj tsis xav teb los tsis ua cas.

PUAS MUAJ NUJ NQIS DAB TSI RAU TUS NEEG TEB COV LUS?
Tej zaum qhov uas koj siv sij hawm los tham yuav tsis muaj nuj nqis dab tsi ncaj qha rau koj. Tab sis, koj cov lus teb yuav muaj nuj nqis rau cov thawj coj hauv cov koos haum tu neeg muaj mob hnyav uas kho tsis zoo kom lawv nkag siab txog Hmoob kev li kev cai tu neeg thiab pab cuam rau lub sij hawm uas muaj mob hnyav. Tom qab koj tsum tsis tham ntxiv lawm, koj yuav

tau txais ib daim ntawv qhia txog cov koos haum uas pab neeg thaib ib dam npa khoom plig uas muaj 25 duas las hauv.

TXOJ KEV UAS TSIS QHIA LWM TUS HAIS TIAS KOJ NROG PEB THAM

Cov lus uas koj hais rau hauv txoj kev tshawb fawb no yuav muab luam tawm rau neeg pej xeem tau nyeem, tab sis yuav tsis siv koj lub npe tsam lwm tus paub hais tias yog koj. Peb yuav siv sawv daws cov lus teb los sau tsheg xwb. Daim ntawv sau cov lus nug, thiab daim ntawv koj tso cai, thiab koj cov lus kaw yuav tsis pub rau lwm tus pom los hnov; yuav muab xauv tseg, tsuas yog kuv no thiaj li yog tus uas yuav tau tus yawm sij los qhib xwb. Ob xyoos tom qab, mam muab daim ntawv sau cov lus nug rhuav tshem. Xya xyoo tom qab mam muab koj daim ntawd tso cai rhuav tshem. Lub sij hawm uas txoj kev tshawb fawb no xaus lawm, mam li muab koj cov lus uas kaw ntawb lwv thiab rhuav tshem.

Yog koj tso cai tham txog ntawm txoj kev tshawb fawb no, kuv xav siv koj cov lus tab sis yuav tsis siv koj lub npe kom lwm tus tsis txhob paub tias yog koj. Yog koj tso cai, thov kos koj lub npe ntawm txoj kab hauv qab daim ntawm no. Thov kos tus niam ntawv ntawm koj lub npe thiab tus niam ntawv ntawm koj lub xeem xwb (initials).

YUAV HU RAU LEEJ TWG YOG KUV MUAJ LUS NOOG?

Yog koj muaj lus noog tsis txhob ua siab deb. Yog koj muaj lus noog tom qab kuv nrog koj tham tag hnub no, koj hu tuaj rau tus thawj coj ntawm txoj kev tshawb fawb no hu ua Tracy Schroepfer ntwam xov tooj (608) 263-3837. Koj hu rau tus ntxhais tshawb fawb hu uas Youhung Her-Xiong ntawb tus xov tooj 608-571-2580 los tau thiab.

Yog koj tsis txaus siab rau cov lus uas tus thawj tshawb fawb teb rau koj, los yog koj muaj lus noog ntxiv thiab xav nrog it tug neeg tham txog koj txoj kev muaj cai ntawm txoj kev tshawb fawb no, koj hu rau lub koos haum Education Research and Social & Behavioral Science IRB ntawm tus xov tooj 608-263-2320.

Qhov uas koj teb cov lus noog tsuas yog nyob ntawm koj tso cai xwb, yeej tsis yuam koj.

Yog koj kos koj lub npe ces txhais tau hais tias koj tau nyeem daim ntawv nov los yog kuv twb nyeem rau koj lawm, tau sij hawm noog txog tej uas koj tsis to taub, thiab koj tau tso cai nrog kuv tham. Koj yuav tau txais daim ntawd nov ua pov thawj khaws tsheg.

Tus teb lus noog lub npe (thov kos lub npe): _____

_____

Thov kos lub npe sib cab Hnub

_____ Kuv tso cai siv cov lus kuv teb tab sis yuav tsis siv kuv lub npe thaum muab kuv cov lus luam tawm.

APPENDIX G

Interview Guide

Caregiving for Hmong Elders During a Time When They Have an Illness that Could Not Be Cured

I would like to thank you for agreeing to talk with me and for letting me ask questions about the care you would like if you had an illness that could not be cured. Your answers will greatly help doctors, nurses, social workers and others who want to provide good care to Hmong people. With you sharing the care you would like to receive, knowledge can be gained on how to best provide care to Hmong.

I will be taking notes during the interview but would like to record our conversation, so I do not miss anything important. Would it be okay with you if I record the interview today?

We will be talking today for about 30 minutes. If you would like to rest or stop our talking, please let me know and we will do so. Please also know that everything you tell me today will be kept confidential; that is, your name will not be written on anything so that no one will know who gave me this information.

Section 1: Demographics
I would like to start by asking you some questions that will help me know you better.

_____ 01. How old are you?

_____ 02. What is your gender?
1. Female
2. Male

_____ 03. What is your marital status?
1. Married
2. Separated
3. Divorced
4. Widowed
5. Single

ASK Q03a IF RESPONDENT IS <u>MARRIED.</u>

_____ 03a. Is your spouse currently living with you?
1. Yes
2. No

04. Would you please tell me your story about how you came to live in the United States?

Prompt: In what year did you come to the United States? (Four digits)

Prompt: In what country were you born?

SKIP TO Q05a IF PARTICIPANT IS ALREADY <u>SPEAKING ENGLISH</u>

_____ 05. Do you speak English?
1. Yes → Go to Q05a
2. No → Go to Q05a

_____ 05a. Do you write in English?
1. Yes → Go to Q06
2. No → Go to Q06

SKIP TO Q06a IF PARTICIPANT IS ALREADY <u>SPEAKING HMONG</u>

_____ 06. Do you speak Hmong?
1. Yes → Go to Q6a
2. No → Go to Q06a

_____ 06a. Do you write in Hmong?
1. Yes → Go to Q07
2. No → Go to Q07

_____ 07. How many years of school have you completed? (Report in years)

ASK Q07a, IF RESPONDENT REPORTS HAVING <u>ATTENDED SCHOOL.</u>
IF NO YEARS OF SCHOOL REPORTED, SKIP TO Q08.

_____ 07a. Did you attend school outside of the United States?
1. Yes → Go to Q7a1
2. No → Go to Q7b

_____ 07a1. In what country did you attend school?
1. Laos
2. Vietnam
3. Thailand
4. Others (Specify)_____

_____ 07a2. How many years did you attend?

_____ 07b. Have you attended school in the United States?
1. Yes → Go to Q07b1
2. No → Go to Q08

_____ 07b1. How many years have you attended?

_____ 08. Are you currently working?
1. Yes → Ask Q08a
2. No → Ask Q08b

08a. What kind of work do you do? _____

SKIP Q08b IF RESPONDENT IS CURRENTLY WORKING

08b. Why are you not working? _____

_____ 09. What religion do you practice?
1. Do not practice any religion → Go to Q09d
2. Christianity → Go to Q09a
3. Animism → Go to Q09a
4. Christianity & Animism → Go to Q09a
5. Other (specify) _____ → Go to Q09a.

_____ 09a. Have you always practiced_____(insert answer from **Q09**)?
1. Yes → Go to Q10.
2. No → Go to 09b.

_____ 09b. What religion did you practice before _____(insert answer from **Q09**)?
1. Christianity
2. Animism
3. Christianity & Animism
4. None
5. Other (specify)_____

_____ 09c. What country were you living in when you practiced _____ (insert answer from **Q09b**)?
1. Laos
2. Vietnam
3. Thailand
4. United States
5. Other (specify)_____

SKIP TO Q10

_____ 09d. Have you always not practiced a religion?
1. Yes → Go to Q10
2. No → Go to Q09e

_____ 09e. What religion did you practice before?

1. Christianity
2. Animism
3. Christianity & Animism
4. Other (specify) _____

_____ 09f. What country were you living in when you were practicing_____ (insert answer from **Q09e)?**
1. Laos
2. Vietnam
3. Thailand
4. United States
5. Other (specify) _____

_____ 10. Do you have children?
1. Yes → Go to Q10a
2. No → Go to Q11

_____ 10a. How many children do you have?

_____ 11. Does anyone currently live with you?
1. Yes → Go to Q11a
2. No → Go to Section 2

11a. Who lives with you? _____

Section 2: Hmong Elders' Acculturation
Next, I would like to ask you some questions about your life in the United States.

12. What is your life like as a Hmong elder living in the United States?

Prompts: Ask these if respondent does not address in Q12.

Prompt: How important is it for you to keep practicing Hmong traditions?

Prompt: How important is it for you to spend time with Americans?

Prompt: What language do you usually speak?

Prompt: Who do you usually go to for support?

Prompt: Who do you usually spend your free time with?

Prompt: Do you usually eat Hmong or American food?

Section 3: Caregiving for Hmong Elders

The questions I am going to ask you now are about the care you would like to receive if you had an illness that could not be cured.

13. Would you please tell me about a time when you took care of someone else?

14. What care would you like if you had an illness that could not be cured?

Prompts: Ask these if respondent does not address in Q14.

Prompt: What types of care commonly practiced in the Hmong culture would you like to receive?

Prompt: Who would you like to provide the care for you?

Prompt: Would you please tell me about the spiritual beliefs that you have regarding the care you would want if you had an illness that could not be cured?

Prompt: Would you please tell me about the spiritual rituals that you would want done if you had an illness that could not be cured?

_____ 15. You have talked about the types of care you would want to receive if you had an illness that could not be cured. Do you believe that you will receive this kind of care?

1. Yes
2. No

15a. Would you please say more about why you feel this way?

_____ 16. You just told me that you would like _____ (fill in respondent's preferred caregiver(s) from above) to provide care to you. Do you think that _____ (respondent's chosen caregiver(s)) will provide this care to you?
1. Yes→ Go to Q17a
2. No→ Go to Q17a

16a. Would you please talk about why you feel this way?

17. If your _____ (respondent's preferred caregiver) could not provide the care for you, who else would you like to give you this care?

_____ 18. After having lived in the United States for the past ___ years (say number of years from Q04), do you feel that the care you would have liked to receive when you lived in_____ (insert country) is different than the care you would want now?
1. Yes
2. No

18a. Would you please talk about why you feel this way?

Section 4: Final Thoughts

_____ 19. Before we stop talking today, is there anything else you would like to tell me about what we talked about?
1. Yes → Go to Q19a
2. No → Go to Q20

19a. What would you like to tell me?

_____ 20. Do you have any questions for me?
1. Yes → Go to Q20a
2. No → Go to Q21

20a. What would you like to ask me?

_____ 21. I want to make sure that I understand what you have shared with me correctly. If I have any questions later, would you mind if I contacted you?
1. Yes → Go to Q22
2. No → Go to Q22

_____ 22. Do you know anyone who might be interested in this study?
1. Yes → Give flyer and letter of introduction to the participant so they can share it with potential respondents
2. No → End interview

Section 5: Post-interview questions (completed by interviewer)

Information about formal/informal referral source.

Agency Name (if applicable): _____

City and State of Agency/referral: _____

Type of Referral Source: _____

Location of Interview: _____

APPENDIX H

Interview Guide in Hmong

Kev Pab Cuam Thiab Tu Cov Laus Rau Lub Sij Hawm Uas Muaj Mob Kho Tsis Zoo

Ua tsaug uas koj tseem xyeej los nrog kuv tham txog lub sij hawm uas yus muaj ib tug mob loj kho tsis zoo es yus ho xav txais tej kev pab cuam zoo li cas. Cov lus uas koj teb yuav muaj nuj nqis rau thaj maum, nawj (nurses), cov pab neeg (social workers), thiab cov neeg uas xav muab txoj kev pab cuam zoo rau Hmoob.

Kuv yuav sau ob peb lo lus thaum wb tham tab sis yog koj tsis xav li cas no kuv xav kaw wb cov lus teev tseg tsam kuv ho tsis nco qab tej yam tseem ceeb uas wb tau tham. Koj puas okay yog tias kuv kaw wb cov lus teev tseg?

Qhov wb yuav tham hnub no ces yuav siv sij hawm li 30 feeb. Yog tias koj tsis khab seev tham lod los yog xav so los tsum tsis tham lawm no thov qhia kuv es wb mam li tsum. Kuv yuav tsis muab koj lub npe lo rau cov lus uas koj hais hnub no kom lwm tus paub.

Tshooj 1: Lus noog txog tus kheej
Kuv yuav noog ob peb nqi lus txog koj tus kheej ua ntej kom kuv ho paub koj zoo me ntsis.

_____ 01. Koj muaj pes tsawg xyoo?

_____ 02. Koj yog?
3. Poj niam
4. Txiv neej

_____ 03. Koj puas muaj txij nkawm?
6. Muaj txij nkawm
7. Sib tso tab sis tsis tau sib nrauj
8. Sib nrauj
9. Poj ntsuam/yawg ntsuam
10. Tsis tau muaj txij nkawm li (single)

NOOG Q03a YOG TIAS TUS TEB <u>MUAJ TXIJ NKAWM.</u>

_____ 03a. Koj tus txij nkawm puas nrog koj nyob?
3. Nrog
4. Tsis nrog

04. Koj piav txog lub sij hawm uas koj tuaj nyob rau teb chaws Ameliskas no.

Noog: Koj tuaj nyob rau teb chaws Ameliskas no xyoo twg? (Saub plaub tug lej)

Noog: Koj yug nyob rau lub teb chaws twg?

MUS RAU Q05a YOG TUS TEB TWB <u>HAIS LUS ASKIV</u>.

_____ 05. Koj puas txawj hais lus Askiv?
1. Txawj → Mus rau Q05a
2. Tsis txawj → Mus rau Q05a

_____ 05a. Koj puas txawj sau ntawv Askiv?
1. Txawj → Mus rau Q06
2. Tsis txawj → Mus rau Q06

MUS RAU Q06a YOG TUS TEB TWB <u>HAIS LUS HMOOB.</u>

_____ 06. Koj puas txawj hais lub Hmoob?
1. Txawj → Mus rau Q6a
2. Tsis txawj → Mus rau Q06a

_____ 06a. Koj puas txawj sau ntawv Hmoob?
3. Txawj → Mus rau Q07
4. Tsis txawj → Mus rau Q07

_____ 07. Koj kawm ntawv tiav pes tsawg xyoo? (Suav xyoo)

NOOG Q07a, YOG TUS TEB TAU <u>KAWM NTAWV.</u>

YOG TUS TEB <u>TSIS</u> TAU KAWM NTAWV, MUS RAU Q08.

_____ 07a. Thaum koj nyob tim ub koj puas kawm ntawv?
3. Kawm → Mus rau Q7a1
4. Tsis kawm → Mus rau Q7b

_____ 07a1. Koj kawm ntawv rau hauv lub teb chaws twg?

5. Teb chaws nplog
6. Teb chaws nyab laj
7. Teb chaws Thaib
8. Lwm lub teb chaws (Yog lub twg)_

_____

_____ 07a2. Koj kawm tau pes tsawg xyoo?

_____ 07b. Koj puas tau kawm ntawv hauv teb chaws Asmeliskas no?
3. Kawm → Mus rau Q07b1
4. Tsis kawm → Mus rau Q08

_____ 07b1. Koj kawm tau pes tsawg xyoo?

_____ 08. Koj puas ua hauj lwm?
3. Ua → Mus rau Q08a
4. Tsis ua → Mus rau Q08b

08a. Koj ua hau lwm dab tsi?

_____

YOG TUS TEB TSEEM UA HAUJ LWM, TSIS TXHOB NOOG Q08b

08b. Vim li cas koj ho tsis ua hauj lwm?

_____

_____ 09. Koj coj kev ntsheeg dab tsi?
6. Tsis coj kev ntsheeg dab tsi → Mus rau Q09d
7. Ntsheeg vaj tswv/lawb dab → Mus rau Q09a
8. Coj kev cai qub → Mus rau Q09a
9. Ntsheeg vaj tswv & coj kev cai qub → Go to Q09a
10. Lwm yam (yog dab tsi) _____ → Mus rau Q09a.

_____ 09a. Koj ib txwm coj _____ (lo lus teb ntawm nqi **Q09**)?

1. Ib txwm coj → Mus rau Q10.
2. Tsis yog → Mus rau 09b.

_____ 09b. Koj coj kev ntseeg dab tsi ua ntej koj hloov los _____ (lo lus teb ntawm **Q09**)?
6. Ntsheeg vaj tswv/lawb dab
7. Coj kev cai qub
8. Ntsheeg vaj tswv & coj kev cai qub
9. Tsis coj
10. Lwm yam (yog dab tsi)

_____

_____ 09c. Koj nyob rau lub teb chaws twg thaum koj coj kev ntsheeg _____ (lo lus teb ntawm **Q09b**)?
6. Teb chaws nplog
7. Teb chaws nyab laj
8. Teb chaws Thaib
9. Teb chaws Asmeliskas
10. Lwm lub teb chaws (yog lub twg)

_____

SKIP TO Q10

_____ 09d. Puas yog koj ib txwm tsis coj kev ntseeg dab tsi?
1. Yog → Mus rau Q10
2. Tsis yog → Mus rau Q09e

_____ 09e. Yav tas los koj coj kev ntseeg dab tsi?
5. Ntseeg vaj tswv/lawb dab
6. Kev cai qub
7. Ntseeg vaj tswv/lawb dab & kev cai qub
8. Lwm yam (yog dab tsi)

_____

_____ 09f. Thaum koj coj kev ntseeg

_____

(lo lus teb ntawm **Q09e)** koj nyob lub teb chaws twg?
6. Teb chaws nplog
7. Teb chaws nyab laj
8. Teb chaws thaib
9. Teb chaws Amelikas
10. L

wm lub teb chaws (sau lub teb chaws)

_____

_____ 10. Koj puas muaj menyuam?
3. Muaj → Mus rau Q10a
4. Tsis muaj → Mus rau Q11

_____ 10a. Koj muaj pes tswag tus menyuam?

_____ 11. Puas muaj leej twg nrog koj nyob?
3. Muaj → Mus rau Q11a
4. Tsis muaj → Mus rau tshooj 2

11a. Leej twg nrog koj nyob?_____

_____

Tshooj 2: Cov Laus Txoj Kev Yoog Thiab Kev Hloov Hmoob Kev Li Kev Cai Nyob Rau Teb Chaws Asmeliskas Thiab Kev Yoog Meskas Kev Li Kev Cai

Txuas ntxiv no mus, kuv xav noog koj txog koj lub neej nyob rau teb chaws Asmeliskas.

12. Koj piav me ntsis txog koj lub neej uas ua ib tug laus nyob rau teb chaws Asmeliskas no.

Noog: Noog cov nqi lus no yog tub teb tsis tau piav thaum nws teb nqi Q12.

Noog: Txoj kev uas yus coj kev cai Hmoob tseem ceeb npaum li cas rau koj?

Noog: Txoj kev uas yus mus sib fim los sib raug zoo rau mekas tseem ceeb npaum li cas rau koj?

Noog: Koj hais hom lus twg ntau tshaj?

Noog: Thaum koj xav tau kev pab cuam, koj mus rau leej twg?

Noog: Thaum koj muaj sij hawm mus ua si, koj nrog leeg twg?

Noog: Koj noj zaub mov Hmoob los zaub mov mekas ntau tshaj?

Tshooj 3: Kev Pab Cuam Thiab Tu Cov Laus
Cov nqi lus uas kuv yuav noog koj tom ntej no yog noog txog txoj kev pab cuam thiab tu neeg rau lub sij hawm uas yus muaj mob kho tsis zoo lawm.

13. Koj piav me ntsis txog ib lub sij hawm uas koj tau tu ib tug neeg uas muaj mob.

14. Ua li yog yus ne, yus ho xav tias kom lwm tus tu yus li cas los yog yus ho xav txais tej kev pab cuam li cas rau lub sij hawm uas yus yuav tsis zoo lawm?

Noog: Noog cov nqi lus tom qab nov yog tus teb tsis tau hais thaum nws teb nqi Q14.

Noog: Cov kev pab cuam los kev tu neeg mob loj uas Hmoob ib txwm uas ne, yus ho xav tau dab tsi

Prompt: Yus ua niam ua txiv yus tsis paub xyov tus twg yuav los hlub yus, tab sis koj ho xav kom leej twg hlub pab thiab tu koj rau lub siab zoo li no?

Prompt: Ua li tej kev cai dab qhuas ua yus ntsheeg tias tseem ceeb rau lub sij hawm zoo li no, yog dab tsi thiab yus puas xav tias tsim nyog ntsheeg?

Prompt: Hos tej kev cai dab qhuas ua yus ib txwm ua rau lub sij hawm zoo li no ne, yog dab tsi thiab yus puas xav tias tsim nyog ua?

_____ 15. Wb tham ntau yam hnub no txog tej kev pab cuam, kev tu neeg mob uas koj xav tau. Ua yog yus ne, yus puas xav tias tej zaum yus yuav tau kev pab cuam li yus ntshaw?

3. Xav
4. Tsis xav

15a. Koj piav me ntsis ntxiv hais tias vim li cas koj ho xav li no.

___ 16. Koj tham me ntsis hais tias yus xav kom _____ (tus xav kom tu/pab yus) pab thiab tu yus. Yus ua niam ua txiv, yus tsis paub xyov leej twg yuav hlub los tsis hlub yus, thaum zoo li no lawm, yus puas xav tias tej _____ puas yuav hlub yus li yus siab xav?

1. Xav
2. Tsis xav

16a. Koj piav me ntsis ntxiv hais tias vim li cas koj ho xav li no.

17. Thaum yus tej _____ pab this tau yus, los sis hlub tsis tau yus thiab tu tsis tau yus lawm ne, yus ho xav kom leej twg los pab thiab tu yus?

_____ 18. Thaum peb nyob tim ub es yog tias peb zoo li no, txoj kev pab cuam ho zoo li cas thiab txawv li cas rau niam no? Peb tuaj nyob rau teb chaws mekas no tau ntau xyoo lawm, tej kev pab cuam thiab kev tu neeg rau lub sij hawm zoo li no puas txawv yog tias peb nyob tim ub?

1. Txawv
2. Tsis txawv

18a. Koj piav me ntsis ntxiv hais tias vim li cas koj ho xav li no.

Tshooj 4: Lus Kawg

_____ 19. Ua ntej wb tsum hnub no, koj puas muaj lus tham ntxiv lawm?
3. Muaj → Go to 19a
4. Tsis muaj → Go to Q20

19a. Koj xav tham dab tsi ntxiv?

_____ 20. Koj puas muaj lus noog kuv?
3. Muaj → Mus rau Q20a
4. Tsis muaj → Mus rau Q21

20a. Koj xav noog kuv dab tsi?

_____ 21. Qhov uas kuv nkag siab tej lus uas koj tau hais rau kuv yog ib qho tseem ceeb heev. Yog tias lwm hnub kuv ho muaj lus noog koj dab tsi ntxiv, koj puas xav li cas yog kuv rov qab hu tuaj nrog koj tham?
3. Tsis xav → Mus rau Q22
4. Xav → Mus rau Q22

_____ 22. Koj puas paub tej tug laus uas xav tham txog tej yam uas wb tham hnub no?
1. Paub → Muab ntawv rau ces tsum qhov sib tham
2. Tsis paub → Tsum qhov sib tham

Tshooj 5: Niq lus noog tom qab tham nrog tus laus (tus tsawb fawb mam li sau cia)

Lub koos haum los yog tus uas muab tus laus npe rau tus tshawb fawb.

Lub koos haum lub npe (yog tias yog lub koos haum): _____

Lub zos thiab lub lav: _____

Tub uas muab tus laus lub npe: _____

Qhov chaw uas ntsib tus laus: _____