

THE PERCEPTIONS OF END-OF-LIFE DECISION  
MAKING AND HOSPICE CARE OF  
IU MIEN ELDERS

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A Thesis  
Presented  
to the Faculty of  
California State University, Chico

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Arts  
in  
Social Work

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by  
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Spring 2015

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Spring 2015

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## DEDICATION

I would like to dedicate this thesis to my parents,

Kao and Lay;

and to all of my siblings,

Mey, Gina, Annie, Diane, and Jade;

and to my relatives,

the Iu Mien Community,

and to all my supportive friends.

## ACKNOWLEDGEMENTS

First and foremost, I would like to acknowledge Dr. Jean Schuldberg for her support and encouragement during the Master's in Social Work program and serving as committee chair for this thesis. Professor Schuldberg's enthusiasm for research and social justice continues to motivate me to excel in the field of social work. Her guidance and supervision contributed to my success in completing this thesis.

I would also like to thank my advisory committee members; Kathy Cox and Lorie Cavanaugh. Professor Cox and Professor Cavanaugh provided great insight, clarity, and guidance during the process. They were always available for consultation and provided quality feedback to assure the success of this thesis.

I would like to thank the thesis editor and advisor, Carson Medley. His suggestions and tips were significant for the completion of this thesis. He was readily available since the beginning of the process for consultation and feedback.

Many thanks to Dr. Chiem-Seng and Kao Thun for your support and collaboration for the research. Your assistance made it possible for completing the research and expanding the knowledge of the Iu Mien community. Additionally, to the participants: your meaningful interviews provided great insight and knowledge for future studies. Thank you so much for your time, energy, and insightful accounts!

Finally, I would like to thank all of my family members, especially my parents, for assisting me in the research and providing great moral support. I would also like to provide a special thanks to my friends, colleagues, and co-workers for their patience, understanding, and continuous support. Thank you, everyone.

## TABLE OF CONTENTS

	PAGE
Publication Rights .....	iii
Dedication .....	iv
Acknowledgements .....	v
Table of Contents .....	vi
List of Nomenclature .....	viii
Abstract .....	ix
CHAPTER	
I. Introduction .....	1
Background .....	1
Statement of the Problem .....	3
Purpose of the Study .....	3
Theoretical Bases and Organization .....	4
Definition of Terms .....	5
Limitations of the Study .....	6
II. Literature Review .....	8
Introduction .....	8
Hospice: Philosophy and Services .....	8
Use of Hospice Services by Southeast Asian and Asian Communities .....	13
The Iu Mien People.....	23
Iu Mien Perspectives of Illness and Death .....	27
Summary .....	29

CHAPTER	PAGE
III. Methodology .....	31
Participants/Sampling .....	32
Instrument .....	34
Data Analysis .....	35
IV. Findings and Results .....	37
Perceptions of Death .....	37
Responses to Death and Dying .....	41
Hospice .....	45
Discussion .....	48
Summary .....	54
V. Conclusions and Recommendations .....	56
Conclusion .....	56
Recommendations for Further Research .....	57
References .....	59
Appendices	
A. Informed Consent/ Consent to Release Information .....	69
B. Survey (English) .....	73
C. Human Subjects Post data Collection .....	76

## LIST OF NOMENCLATURE

CAN	Certified Nursing Assistant
EOL	End-of-life
MHB	Medicare Hospice Benefit
NHPCO	National Hospice and Palliative Care Organization
RN	Registered Nurse
WHO	World Health Organization

## ABSTRACT

### THE PERCEPTIONS OF END-OF-LIFE DECISION- MAKING AND HOSPICE CARE OF IU MIEN ELDERS

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The use of hospice services has increased over past 10 years, but minority access has been limited (Harber, 1999). In order to better understand the reasons for limited access to hospice by the Iu Mien community, this study explored the perceptions of death, end-of-life (EOL) decision-making, and attitudes about hospice philosophy of Iu Mien elders (N = 8). The Iu Mien community in the United States is small (approximately 35-50,000) (Barker & Saechao, 1997; Macdonald, 1997; Schuldberg, 2005) with unique spiritual and religious beliefs. Since the literature is limited on this population, it is vital to learn about how to better serve their community. The results of the study indicated that not only is the Iu Mien community influential in an individual's perception of death and dying, but that there is a need for culturally sensitive educational outreach regarding EOL care, including hospice services, to the Iu Mien community.

## CHAPTER I

### INTRODUCTION

#### Background

With the United States' older population of 65 years and older growing by 10,000 persons each day (U.S. Census Bureau, 2011), a greater number of services and trained workers will be needed to meet our aging population's social, physical, and spiritual needs. Understanding perceptions regarding end-of-life (EOL) matters will be of great importance. Thus, in order to address the U.S.' increasing minority population, it is paramount that EOL care needs, including the use of hospice services, are understood in a cultural context.

Out of the 1.65 million people who received hospice care in 2012, about 2.4% were of Asian descent (NHPCO, 2012). The U.S. Census Bureau (2011) projects that between 2012 and 2030, the Asian American population of adults 65 years and older will increase by 119% (U.S. Department of Health and Human Services, 2013b). The Asian American population consists of 10.3% older adults, while 9.5% of African Americans and 7% of Hawaiian and other Pacific Islanders are within this age group (U.S. Department of Health and Human Services, 2013b).

Most EOL issues have been framed in the context of Western values and beliefs while excluding the views of other cultures (Blank, 2011). Blank (2011) suggests the need for more emphasis on understanding how other cultures view EOL issues in

order to create better policies to meet the needs of most individuals in American society. This is important especially since Asian Americans are understudied with regard to hospice and EOL care (Jang, Chiriboga, Allen, Kwak & Haley, 2010; Kwak & Salmon, 2007; Smith, Smith, Earle & McCarthy, 2009). What literature there is tends to focus on Japanese, Chinese, and Korean Americans. There is extremely limited data regarding EOL views and the use of hospice services from the perspective of Southeast Asian Americans.

For this study, the researcher will explore the perceptions of EOL and hospice care held by a particular understudied group of Asians in the United States, the Iu Mien people who are also known as the Yao, Yiu Mien, or Mien (Barker & Saechao, 2000; Macdonald 1997). The above names are used interchangeably in this research. The Iu Mien people immigrated to the United States in the 1980s as refugees from the Secret War in Southeast Asia (McDonald, 1997). The most recent demographic data on the number of Iu Mien people in the United States is from 1995 and reports the number as 35,000 (McDonald, 1997). The lack of current data on the number of Iu Mien in the United States, as well as the limited research on the community's culture and needs, highlights the need for research on the Iu Mien population

### Statement of the Problem

This study examined the views of Iu Mien elders regarding EOL decision-making and hospice care. In comparison to other hill tribe groups from Southeast Asia, such as the Hmong people, there has been relatively little research on the Iu Mien (Barker & Saechao, 1997; Ying & Chao, 1997). More specifically, for the older adult population of the Iu Mien in California, there are little to no studies (Barker & Saechao, 1997). Thus, there is a lack of information on the Iu Mien community's perspectives and decision-making regarding EOL and hospice care. With the increase in our older population, which includes the Iu Mien, and the need for 70,000 more social workers in the United States versed in gerontology by 2030 (Council on Social Work Education, 2014), there is also a need for cultural competent practitioners to serve Iu Mien older adults and their families.

### Purpose of the Study

The purpose of this research is to understand the views and perceptions of Iu Mien elders on topics related to EOL and hospice care. Currently, there is no research available about hospice services for the Iu Mien community. This study will enhance the limited literature on this population and serve as a foundation to help guide practitioners when working with this specific population. As we live in an aging society, there will be more of a demand to provide hospice services for older adults. This research will help professionals become more culturally competent in working with Iu Mien elders and their families.

The core values of cultural competence and social diversity indicates that a social worker should not only “understand culture and its function in human behavior and society,” but needs to also be educated and “demonstrate competence in the provision of services that are sensitive to clients’ cultures and to differences among people and cultural groups” (NASW, 2008, 1.05). This study also aligns with the NASW value of evaluation and research as it “promote and facilitate evaluation and research to contribute to the development of knowledge [and] “critically examine[s] and keep[s] current with emerging knowledge relevant ...to use ...in their professional practice” (NASW, 2008, 5.02).

#### Theoretical Bases and Organization

The methodology guiding this research is grounded theory, which is based on the understanding that theory is built up from information “grounded” in data. This theory is also known for its methodology in organizing data. Grounded theory is rooted in the process of collecting data while simultaneously analyzing it for emerging codes and themes, and eventually culminating in theory “grounded” in the data (Charmaz, 2014; Patton, 2002). O' Connor, Netting, and Thomas (2008) found that grounded theory is used for comparative means and to establish deep meanings.

Grounded theory attempts to integrate quantitative methods into qualitative research, by combining in-depth interviews with logical and systemic analysis approaches (Walker & Myrick, 2006). The systematic process of line by line coding of qualitative data allows for the experiences of participants to be what guides the emerging

themes and concepts (Charmaz, 2014; Strauss & Corbin, 1997). The data analysis process used for grounded theory is helpful in organizing categories through coding, producing memos and notes, and then writing theories based on these memo and categories (Walker & Myrick, 2006). In this case, themes emerging from line by line coding categorizes the answers of the questions regarding perceptions of EOL decision-making and hospice care from the Iu Mien community.

#### Definition of Terms

##### Acculturation:

"Cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture; *also*: a merging of cultures as a result of prolonged contact " (Merriam-Webster, 2015, n.p.).

##### Collectivistic:

"Many decisions are not made by individuals, but by families and groups, presumably with the larger good in mind" (McLaughlin & Braun, 1998, n.p.).

##### Cultural competency:

"As the incorporation of diversity (facts), awareness (knowledge), and sensitivity (attitude) into everyday practice and behaviors" (Doorenbos & Schim, 2004, p. 28).

##### Filial piety:

"Filial piety refers to the obligation of family members to care for each other, with a particular obligation for the younger generation to care for the older generation and family ancestors" (McLaughlin & Braun &, 1998, n.p.).

### Palliative care:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2015, n.p.).

### Limitations of the Study

There are several limitations related to this study. This researcher's primary language is English with conversational skills in the Mien language. Due to a lack of understanding of some concepts and words in the Mien language, translating from English to Mien was an arduous process; approximately 25% of English words could not be precisely articulated into the Mien language. Open-ended questions such as "How is death viewed in your community?" and "What does death mean to you?" developed for the interviews were a challenge to translate. This researcher needed to rephrase questions to be closed-ended and add examples to provide greater clarity. For example, the term "community" was translated into Mien as "us people." This English-to-Mien translation initially caused confusion as the participants provided an interpretation of their ideas rather than those of the community for which the question focused. The challenge with language frequently presents as a research limitation when questions and terms are lost in translation (Demiris, Oliver, Capurro, & Wittenberg-Lyles, 2013; Meyer, Young, & Lieberstein-Solera, 2012; Pena, 2007).

In addition to challenges with language, the limited time frame and constraints of the research did not permit a larger sample size. The researcher was introduced to potential participants by a member of the center where the interviews took place, but due to cultural factors, there was a need for a community leader to be the "gatekeeper" for a formal introduction of the researcher to the subjects. The small sample size of eight provided a good introduction to this topic, but a larger sample size would have provided more enriching information. Additionally, the data collected reflected only the views of females, thus a gender bias was present. Males were asked to participate in the research during the recruiting process, but they seemed hesitant and declined two invitations to participate in the study.

The sample size also consisted of women between the ages of 62 and 81. They had all immigrated to the United States as refugees when they were ages 25 to 45. Thus, this study was limited to those from a specific cultural orientation that originated in their home community of Laos, and those individuals of a specific age range.

## CHAPTER II

### LITERATURE REVIEW

#### Introduction

This review of the literature begins with an overview of hospice philosophy and services. This is followed by an analysis of the literature on the use of hospice services by members of Asian American communities and Southeast Asian American communities. The final focus of the literature review is on the Iu Mien people, including their history prior to and when they settled in the United States, roles within the family, religious perspectives, and cultural patterns in relation to death and dying.

#### Hospice: Philosophy and Services

Hospice is a program that provides support for people who are terminally ill or chose not to continue with curative treatment (Connor, 2007; U.S. Department of Human and Health Services, 2013a). Additionally, hospice is:

considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. (National Hospice and Palliative Care Organization [NHPCO], 2012, n.p.)

Hospice is a holistic approach that includes a team consisting of a physician, nurse, counselor/chaplain, medical social worker, home health aides, homemakers, volunteers, a medical director, and other professionals (Connor, 2007; NHPCO, 2012). As well as the support of professionals, hospice services also include medication, medical supplies, and equipment (Connor, 2007; Corcoran & Kapo, 2009).

Hospice professionals form an interdisciplinary team, creating a plan of care for the patient. This may include deciding suitable medication, respite services, as well as physical, occupational, and speech therapy (Connor, 2007; Corcoran & Kapo, 2009). All of the team members are needed "to address the physical, spiritual, and psychosocial aspects of suffering" (Corcoran & Kapo, 2009, p.777).

Volunteers are also a vital part of the patient care; they support patients by building close personal relationships to address the psychosocial and spiritual needs of the patients (Pesut, Hooper, Lehbauer, & Daihuisen, 2014). Hospice also offers bereavements services for the family of the deceased patient for approximately twelve months (Corcoran & Kapo, 2009). With the array of available services provided through governmental certified hospice programs, patients and their family members can choose the services they wish to utilize (Pesut et al., 2014). Hospice was developed from palliative care services which would focus on individuals with challenges with symptom control and who were seriously ill, but not terminally ill (Connor, 2007). Hospice is considered the "gold standard for care of the dying and palliative medicine" (Crawley & Singer, 2007, p. 20).

An excellent example of the scope of hospice services is provided by Weflen (2014) who described the care of his father by a hospice team. Each day he had different team members come to the house to assist him with a specific need. Weflen's father was served by a registered nurse (RN), social worker, certified nursing assistant (CNA), and a chaplain. Each team member assisted in several ways; the RN monitored pain and medication needs, the social worker and chaplain discussed death and end-of-life issues, and the CNA helped with personal hygiene maintenance. When death was imminent, the team members helped his father feel comfortable and the passing was described as "peaceful." Weflen (2014) stated, "I was always appreciative of the hospice crew...they are the last responders" (n.p.).

Hospice can provide many benefits to society, yet it remains underutilized (Colon & Lyke, 2013; Ngo-Metzger, Phillips, & McCarthy, 2008; Ogle, Mavis, & Wyatt, 2002). With the baby boomer generation reaching age 65, and with more older adults living longer, the topic of making the dying process natural and humane has become more prevalent in the literature (Miller & Mike, 1995; Ngo-Metzger et al., 2008). Research has indicated that hospice improves the quality of care at the end-of-life (Connor, 2007; Ngo-Metzger et al., 2008). Recipients of hospice care report higher rates of satisfaction compared to those who have not received this holistic care (Connor, 2007). In addition to the psychosocial benefits, hospice reduces costs in regard to medical and institutional care; this reduces state and federal financial support and, in turn, saves money (Bogasky, Sheingold, & Stearns, 2014; Miller & Mike, 1995).

### Palliative Care

One component of hospice is to provide palliative care. According to the World Health Organization [WHO] (2014), palliative care "improves the quality of life of patients and their family" by providing comfort care addressing the "physical, psychosocial and spiritual" needs of the patients (n.p.). For example, palliative care includes treatment and relief of pain and other distressing symptoms. The philosophy of palliative care is that it neither increases nor decreases a person's life, but instead focuses on providing comfort care (WHO, 2014). Essentially, hospice provides palliative care, but specifically for individuals with a terminal illness with a prognosis of six months or less (Connor, 2007; Get Palliative Care, 2012). In general, individuals can use palliative care without a prognosis while seeking curative care (Get Palliative Care, 2012). According to the National Institute of Nursing Research (2009) a patient can "receive palliative care at the same time you receive treatments that are meant to cure your illness" (p.2). A patient does not have to be receiving hospice services or be considered terminally ill to receive palliative care (Connor, 2007).

### Hospice Care History in the United States

The hospice philosophy was adopted from the United Kingdom and introduced into the United States (U.S.) in the 1960s (Connor, 2007). By 1974, the first hospice program was created in an effort to assist dying patients with pain management, while maintaining them in their home (Connor, 2007). This program was influenced by the U. S. culture of "independence and the distrust of medical institutions" (Connor,

2007, p. 90). Hospice programs were seen as providing independence for patients to choose the type of care they desired during their dying process (Connor, 2007).

In an effort to meet the financial needs of individuals utilizing hospice services, the Medicare Hospice Benefit (MHB) became a permanent funding program in 1985 (Connor, 2007). The United States government allotted a set amount of money to reimburse hospice programs for their services (Connor, 2007). Over 12 billion dollars has been spent for the MHB (Centers for Medicare & Medicaid Services, 2011). The MHB reimburses certified hospices for the following services: home care, twenty-four hour home care during a crisis, inpatient respite care for up to five days or 20% of the hospice care, and general in-patient care at a hospital for symptom management (Bogasky et al., 2014; Connor, 2007).

Under the MHB, Medicare-certified hospices are reimbursed initially for up to six months of care (Smith, Seplaki, Biagtan, DuPreez, & Cleary, 2008; Miller & Mike, 1995). However, a patient may be re-certified if needed for additional time if s/he continues to meet the criteria for hospice care. Medicare will continue pay for the recertification (Connor, 2007; Smith et al., 2008). Although, hospice care can be for an extended period of time, Smith et al. (2008) found that patients are enrolled in hospice services on average of 15.6 days.

According to the NHPCO (2012), over 1.65 million Americans have received hospice care services. There has been significant increase in the utilization of hospice programs from 23% in 2000 to 44% in 2010 (MedPAC, 2013). Although studies indicate

that consumers are satisfied with hospice services, hospice continues to be an underutilized program (Connor, 2007; Smith et al., 2008) due to "physician treatment preferences, patient and family preferences, and available information" (Bogasky et al., 2014, p. E2). The lack of knowledge about hospice and the unavailability of information on local hospice programs has impacted the level of referrals made by physicians and other health care professionals (Corcoran & Kapo, 2009; Friedman, Harwood, & Shields, 2002; Ogle et al., 2002; Smith et al., 2008). Additionally, preferences of patients and their family has impacted enrollment. For some, enrolling in hospice indicates understanding of a terminal status as the patient is forfeiting curative treatment and agreeing to comfort care (Corcoran & Kapo, 2009; Bogasky et al., 2014). For these individuals, the idea of dying is difficult to accept (Bogasky et al., 2014; Miller & Mike, 1995).

#### Use of Hospice Services by Southeast Asian and Asian Communities

##### End-of-Life Care Perspectives

Kwak and Haley (2005) examined current research on EOL decision-making by racial and ethnic groups and discovered startling differences. EOL decision-making involves the discussion of preferences for the EOL. This is completed through the use of Advance Directives, which is a document that outlines a patient's preferences regarding treatment options and choosing a primary health care agent to make decisions when the patient no longer is able to do so (Kwak & Haley, 2005). Several studies found that Asian Americans were less likely to complete advance directives compared to other racial groups, but they would have an informal, primary agent chosen as their health advocate

(Kwak & Haley, 2005). Those who had completed the advance directive were more likely to be enrolled in special services (such as home health care) that would have workers to educate and assist in completing the health directive (Kwak & Haley, 2005).

The lack of discussion regarding EOL care and dying is a pattern among certain Asian American groups (Kwak & Salmon, 2007). The majority of the literature in this area is written on those from Japanese, Chinese, Korean, and Hmong communities. This research will be discussed first in the analysis of the literature.

Japanese Americans' perspective on EOL and hospice care. In Asian American groups that are considered acculturated, such as the Japanese American community, research has indicated that there has been predominately positive attitudes towards advance directives (Kwak & Haley, 2005). A study by Colclough & Young (2007) revealed that Japanese American family members would abide by their loved one's wishes, even though they might not be in agreement with the request. This study concluded that acculturation may have influenced the high percentage of completed advance directives for Japanese American families, which were also verbally discussed with the patient within the family prior to an individual becoming deceased (Colclough & Young, 2007). It is interesting that discussions about an individual's illness and EOL care may include all family members and the physician, but may exclude the patient (Blank, 2011). In contrast to the completion of advanced directives by Japanese Americans, research on the native Japanese revealed that there was no discussions on

EOL decision-making due to the cultural norm of showing respect to the patient and their family (Blank, 2011).

Choi et al. (2012) studied the bereaved family members of individuals using home hospice. This study found that Japanese individuals who were told that treatments would not be helpful to treat cancer interpreted this as meaning they were “near death” (p. 499). Choi et al. (2012) found that many participants believed hospice was appropriate and that there was a correlation with higher rates of acceptance of hospice when a patient’s preferences were taken into consideration, s/he had knowledge of all care and treatment options, s/he had identified a decision maker, and it seemed that the hospice care would be short-term. A patient’s prognosis that indicated a duration of less than 60 days of hospice care reportedly helped bereaved Japanese family members become more accepting of the services (Choi et al., 2012).

Although research found that many Japanese Americans were accepting of hospice, other research provided contradicting data. Colclough and Young (2007) found that when hospice is entangled with the view of palliative care and not curative care, Japanese individuals might not agree to use hospice services at the EOL. This could be due to the traditional Japanese belief that "aging and death are a part of the cycle of life" and should not be disrupted (Colclough & Young, 2007, p. 205). Using hospice was seen as disrupting this cycle as the patient and family were making the decisions about dying. Kwak and Haley (2005) found that Japanese Americans were less likely to prolong life by opting out of using life-support measures.

The literature indicated that Japanese Americans favor a more "family-oriented model instead of individual oriented model" in making EOL decisions (Colclough & Young, 2007, p. 202). Using hospice would involve a level of independent decision-making and this was seen as possibly interfering with the more interdependent Japanese culture. Therefore, EOL decision-making may conflict with traditional values (Colclough & Young, 2007).

Chinese Americans' and Korean Americans' perspective on EOL. Studies have indicated that Chinese American and Korean American older adults believe that discussing death is inappropriate because it can cause bad luck (Kwak & Haley, 2005). For example, the literature indicates that Chinese Americans may prefer to maintain secrecy and avoid other third parties, such as a physician or health professional, from revealing the patient's terminal illness; however, family members may tell the patient. (Mazanec & Tyler, 2003).

There is conflicting research regarding Chinese Americans and decisions to prolong life if they were given a terminal diagnosis (Enguidanos, Yonashiro-Cho, & Cote, 2013). For example, Kwak and Haley (2005) stated that Chinese Americans chose to use all life support measures available. From the research, it appeared that Chinese American and Korean Americans elders would be less likely to disclose their prognosis to other family members, though similar to Japanese Americans, this decision differed according to the level of individual acculturation (Colclough & Young, 2007; Jang et al., 2010).

The majority of the literature on hospice care with Chinese Americans and Korean Americans focuses on the Korean community. A study by Jang et al. (2010) compared Korean Americans to Euro-American and African Americans in the United States and found that Korean Americans were the least likely to have positive views toward EOL decision-making. Crawley & Singer (2007) indicated that Korean Americans were less likely to complete an advance directive and had one of the highest disapproval ratings among other Asian communities for completing advance directives (Crawley & Singer, 2007; Jang et al., 2010). Kwak and Salmon (2007) stated that Korean older adults felt it was unnecessary to complete advance directives as the family made the final EOL decisions. Their study revealed that Korean Americans elders preferred indirect communication about EOL care issues and their children relayed that this indicated more respect and sensitivity towards their parents. However, their adult children who were their designated caregivers, expressed the advantage of an advance directive as a guide to assist with the EOL decision-making process (Kwak & Salmon, 2007). The differences in perspectives about advance directives could be attributed to level of acculturation of Korean Americans (Kwak & Salmon, 2007); acculturation also made a significant contribution to whether an individual would consider using hospice during EOL (Jang et al., 2010).

Jang et al. (2010) found that when chronic conditions exacerbated, there was an increase in willingness to use hospice by Korean Americans. Despite being less likely to discuss EOL care decisions, approximately 73.6% of participants in the study were

willing to consider using hospice when the time was appropriate to use the services. Most caregivers found that hospice allowed them to exercise filial piety, while at the same time providing comfort care. This was preferred due to reported concerns of potential pain resulting from a treatment method. It is interesting to note that Chinese Americans also positively viewed hospice services as a way to relieve pain, but believed that the hospital provided the best quality of care (Enguidanos et al., 2013).

Vietnamese Americans' perspective on EOL. In the Vietnamese culture, it can be culturally inappropriate to discuss death in advance due to issues of stigma. Pham (2010) found that discussing EOL issues and hospice care indicated that one was accepting death. This would then result in an individual being labeled as dying which had cultural consequences, such as the adult children not having filial piety. The adult children would be perceived as not trying their best to care for their loved one. In Pham's (2010) study, older adult Vietnamese Americans expressed interest in returning back to Vietnam towards the EOL to be with close family members. Crawley and Singer (2007) presented a case study regarding cultural norms specifying that a wife cannot partake in making EOL care decision or life-saving care, such as intubation, for her husband. These decisions reportedly had to be made by the husband's father or brother (Crawley & Singer, 2007, p.27). Lee, Phan, & Tran (2005) explained the importance of family in making EOL decisions to avoid "worrying" the patient. Typically the eldest son was the responsible party in making EOL decisions. Pham (2010) discusses the education on advance directives initiating older adults to start considering about EOL care. Pham

(2010) found that the Vietnamese American's responses to questions regarding hospice care indicated that the view of this care denoted positive changes in the Vietnamese community and that some are "getting used to the idea" of it (n.p.).

Hmong Americans' perspective on EOL. It is important to note that individuals from the Hmong community arrived in the U.S. from Southeast Asia in 1975, similarly to that of the Iu Mien people who are the focus of this research study (Gerdner, Cha, Yang, & Tripp-Reimer, 2007; Helsel, Mochel, & Bauer, 2004; Pinson-Perez, 2004). The Hmong people became refugees due to their involvement in the Secret War; they chose to be pro-Western and assisted the U.S. forces. This involvement resulted in losing their homeland and a forced relocation to the U.S. (Gerdner et al., 2007; Helsel et al., 2004; Pinson-Perez, 2004). The data on the Hmong population is quite comprehensive. It is important to note that the Hmong culture is similar to that of the Iu Mien.

According to Gerdner et al. (2007), the Hmong's family structure needs to be taken into account when it comes to making decisions involving EOL care for an individual in the family. In some families, the eldest male is the decision maker and may guide the family in making judgment regarding issues about EOL care and death (Gerdner et al., 2007; Yue-Kong, 1990). In other families, the youngest sons and their wives are responsible for their aging parents including EOL care (Ember & Ember, 2004).

Accepting hospice care typically means accepting the fact that one is terminally ill (Colon & Lyke, 2013). Illness is negatively viewed in the Hmong culture

(Colon & Lyke, 2013). This presents a challenge in regard to hospice care as patients who are admitted to this care are required to have a six-month prognosis, thus indicating the existence of a terminal illness. In the Hmong culture, illness represents the possibility of an ancestor reaching out to the human soul because they are experiencing unhappiness; the family is responsible to discover the reasons behind it (Yue-Kong, 1990). On some occasions, a shaman helps mediate that process (Yue-Kong, 1990).

In the Hmong culture, talking about death is prohibited because it is seen as advancing a person's death and will open the gate for evil spirits to roam on earth (Gerdner et al., 2007). Additionally, the hospice philosophy can create conflict for Hmong American families since it requires patients to refuse life-prolonging interventions which can be seen as being disrespectful to the hospice patient (Gerdner et al., 2007, p. 23). In contrast, the possibility of dying in the home is important to Hmong American elders (Ember & Ember, 2004; Gerdner et al., 2007) and thus hospice might be beneficial to serving their needs. Ember & Ember (2004) related that a "good death" (p. 740) involved a pain-free passing in the home.

For funeral planning, a shaman is used to help guide the deceased person into the afterlife (Ember & Ember, 2004; Yue-Kong, 1990). Funeral planning is required in hospice to help the family members prepare before a crisis occurs. This poses a challenge as reportedly Hmong people are not likely to have a "western outlook and medical practices prior to their departure from Southeast Asia" (Yue-Kong, 1990, p. 46). However, it is noted that Hmong Christians may be more open to western practices.

Thus, each patient's experience is unique and must be acknowledged among professionals (Yue-Kong, 1990).

#### Overall Factors Influencing the Use of Hospice Services by Asian American Communities

The literature indicated that the sharing of EOL decisions and receptiveness to hospice services was dependent on the level of acculturation (Colclough & Young, 2007; Jang et al., 2010) and status of the patient within the family (Pham, 2010). A study by Smith, Earle, and McCarthy (2009) supported the previous literature discussed, relating that Asian Americans had the lowest enrollment and length of stay in hospice. They were also more reportedly more likely to have high-intensive care hospital stay before death (i.e. 14-days) or multiple hospital visits at the EOL than compared to Euro-Americans (Smith et al., 2009). In contrast, Euro-Americans reportedly preferred to have hospice care for three months or longer (Choi et al., 2012; Crawley & Singer, 2007).

Challenges/Barriers to utilizing services. A review of the literature revealed that there may be some inequities in offering hospice services to ethnic minorities. This in turn would impact whether the groups have access and knowledge about hospice care services and affect their perceptions of end-of-life and hospice care (Ngo-Metzger et al., 2008; Roscoe & Schonwetter, 2006; Smith et. al., 2009). In comparison to other racial/ethnic groups, Asian Americans were less likely to use hospice services (Colon & Lyke, 2013). According to Colon & Lyke (2013), there were only 2.4% of Asians who reported using hospice services.

Additionally, studies indicated that the low use of hospice services were due to Medicare-certified hospice agencies not having enough staffing to complete outreach or create more language-friendly brochures for diverse communities. According to Haber (1999), research indicated that there is a lack of volunteer and staff of similar ethnic or racial backgrounds to potential clients. He provided solutions to address the challenges such as collaborations with minority organizations and leaders to spread knowledge and awareness about hospice services. The lack of cultural competence in staff has been correlated to the small number of minorities enrolled in hospice (Doorenbos & Schim, 2004; Reese & Beckwith, 2014).

Organizational culture was believed to be another barrier for minorities to access and utilize hospice services (Reese & Beckwith, 2014; Roscoe & Schonwetter, 2006). For hospices that do not have a culture of encouraging cultural competence in the work force, it is challenging to recruit diverse staff and patients. Additionally, according to Reese and Beckwith (2014), many hospices have reasoned that their lack of educational outreach to minorities was due to inadequate funding. The lack of funding made it difficult to hire a diverse staff and to create more linguistically appropriate educational tools and/or training. Others have found that the lack of knowledge about hospice was attributed to the unavailability of information on local hospice programs; this would impact referrals made by physicians and other health professionals to local hospice programs (Corcoran & Kapo, 2009; Roscoe & Schonwetter, 2006; Smith et al., 2008). One solution was to encourage more palliative care consultations for potential hospice

patients so they are informed and could be referred to hospice services (Bell, Kuriya, & Fischberg, 2011).

Roscoe & Schonwetter (2006) discussed family as another barrier to accessing hospice services. Some families can pressure patients to continue seeking curative care. Studies indicated that many individuals from ethnically diverse communities may view accepting hospice as “giving up” or losing hope for a cure (Friedman et al., 2002; Roscoe & Schonwetter, 2006). One study revealed that cultures may also view hospice as a "white, middle-class, phenomenon" and would distrust that they would receive the same level of care since they are from a different ethnic background and class (Roscoe & Schonwetter, 2006, p.48).

### The Iu Mien People

It is important to understand the history and culture of the Iu Mien people as this impacts perspectives on end-of-life, and the care that might ensue. The Iu Mien in America are small in size compared to other Asian American counterparts (Fitzpatrick, 2009). They have a unique culture and heritage. Further exploration of the Iu Mien will enhance the literature.

#### History of the Iu Mien People

According to Lewis (1992), the Iu Mien people originated from the Southern part of China approximately 2,000 years ago. The Chinese culture would come to influence the language and cultural traditions of the Iu Mien (Fitzpatrick, 2009). Historically, the Iu Mien have been known to be hill-tribesmen, mountain people,

residing in the highlands of China, Vietnam, and Laos (Schuldberg, 2005; Ying & Chao, 1996). The Iu Mien lived in their own remote villages throughout Southeast Asia as farmers and artisans (Barker & Saechao, 2000).

When Laos, South Vietnam, and Cambodia fell to the Communist regime in 1975, Iu Mien people had to flee from persecution as a result of their involvement in the “Secret War.” During the 1970s, the Iu Mien from Laos were contracted by the CIA to stop Communist advancements in Southeast Asia (Baker & Saechao, 2000; Schuldberg, 2005; Ying & Chao, 1996). Since 1975, many Iu Mien have immigrated to other parts of the world including Canada, New Zealand, France, and the United States (Fitzpatrick, 2009). Most Iu Mien resettled in the United States (Fitzpatrick, 2009; Macdonald, 1997; Ying & Chao, 1996).

In 1997, there were approximately 35,000 – 50,000 Iu Mien people who had resettled in the United States (Barker & Saechao, 1997; Macdonald, 1997; Schuldberg, 2005). According to Niedzwiecki and Duong (2004), the Southeast Asian groups of refugees included individuals from Cambodia, Laos, and Vietnam. The Iu Mien and several other groups from Southeast Asia, excluding the Hmong people, have been group categorized in the U.S. Census Bureau as “Laotian” (Niedzwiecki & Duong, 2004). In the 2000 census, there were approximately 198,000 Laotians living in America (Niedzwiecki & Duong, 2004). Today's Iu Mien population size remains inconclusive. Dr. Chiemseng, an Iu Mien scholar, estimated that there are a total of 40,000 Mien individuals

nationwide, but there is no official governmental figure on the population numbers (personal communication, February 28, 2014).

Due to the lack of accurate data regarding the demographics of the Iu Mien, there is a current California bill (AB 176) that, if passed, will collect data on public health and educational disparities of underrepresented minorities within the Asian American and Pacific Islander community (Iu Mien Advocates, 2014). A petition is circulating calling for California Assembly member Bonta to include Iu Mien as an identifiable group on the bill before it is signed into law. If this bill passes, the census data regarding Iu Mien in California will be the first update since 1997.

Settlement in the United States. Similar to the Hmong people, the Iu Mien people were forced to resettle outside of Southeast Asia. Due to an abrupt flight from their homeland, the Iu Mien had difficulty adapting to the culture of the U.S. despite the aide of others (Fitzpatrick, 2009). The events leading to the resettlement impacted the physical and mental well-being of the older Iu Mien generation. Elders reportedly exhibited more anxiety and depressed moods when compared to their children born in the U.S. The elders also developed post-traumatic stress disorder (PTSD) (Barker & Saechao, 2000). As a result, there have been challenges in adapting to life in the U.S.

Iu Mien family roles. Traditional family roles have been changing in Iu Mien families since their resettlement to the U.S. In some instances, the traditional hierarchal family structure remains intact with multi-generations living in the household (Ying & Chao, 1996). In this structure, elders have the highest position of power. Children are

expected to be filial and place their parent's needs over their own. Children are also expected to be dependent on their parents for support and guidance; this is reversed when the children become adults (Ying & Chao, 1996).

There is a Mien proverb stating "a person is an adult once, but a child twice" (Ying & Chao, 1996, p. 51) since adult children are expected to care for their aging parents. Additionally, adult children are expected to perform worships to deceased family members in return for protection and well-being. However, in the U.S., the values differ as American culture emphasizes independence and self-sufficiency.

Younger generations differ in their perceptions of roles compared to the older generations (Fitzpatrick, 2009). Roles are also reversed as children raised in the United States develop competencies related to the U.S. culture at a higher rate than their parents. In the traditional roles, older men were central figures of Iu Mien society as they were spiritual healers. However, roles have changed due to Western values and since many of the younger generations have changed from Taoism to Christianity (Barker & Saechao, 2000). Thus, it appears that religion plays an important role in decision-making for the Iu Mien people (Barker & Saechao, 2000; Fitzpatrick, 2009).

Religion and the Iu Mien people. Ying and Chao (1996) discussed the importance of religion as being a part of the Iu Mien identity and culture in Laos. The traditional Iu Mien religion is a combination of ancestral worship and Taoist animism (Barker & Saechao, 1997; Ying & Chao, 1996). The religious practices involve offering

ceremonies with animal sacrifices to ancestors (Saeyang, 2003; Ying & Chao, 1996). Also, the ceremonies are seen as providing good fortune for health and addressing spirits.

In Laos, men had key roles in the ceremonies in the hierarchical structure of the Iu Mien society. Many men took on the roles as ritual and spirit healers, also known as shaman. Shamans perform healing rituals and ceremonies to ensure health and prosperity or to ward away lecherous spirits for many members in the Iu Mien community (Barker & Saechao, 1997; Saeyang, 2003).

Fitzpatrick (2009) noted that there has been a shift in perspective of religion since Iu Mien refugees settled in the United States. The younger generation in the U.S. is seen as having a choice between practicing Christianity or Taoist Animism, or neither. The older generation, those born in Southeast Asia and coming to the U.S. as adults, reportedly do not believe the newer generation will keep the old customs and traditions of the religious ceremonies (Ying & Chao, 1996). It is believed that older individuals, especially older men, are vital to preserving the spiritual well-being of the Iu Mien community (Barker & Saechao, 1997). The Iu Mien elders are known to have a wealth of knowledge about culture, tradition, and history (Barker & Saechao, 1997). They played a key role in the "temporal as well as spiritual welfare of the mien family or household" (Barker & Saechao, 1997, p. 124).

#### Iu Mien Perspectives of Illness and Death

As with all research conducted on Iu Mien Americans, research on their perceptions of EOL decision-making and hospice is sparse. The Iu Mien people view

death as a separation of the various souls present in a person's body (MacDonald, 1996). Similar to the Chinese, the Iu Mien believe they have ten souls, in which three are from the head and seven are from the body (MacDonald, 1996). It is believed that when the souls leave the body, the person becomes deceased (MacDonald, 1996). This "rite of separation" (MacDonald, 1996, p.177) involves three funeral ceremonies throughout the year, which typically last from three days to a week (fayes86, 2014). A shaman or priest is used to help guide and direct the deceased individual to the "spirit door" to find their new home within the forty-eight levels of the afterlife below the earth (MacDonald, 1996, p.178). The higher the level the individual resides in, the more merit the person had during their time in the living world (MacDonald, 1996). Additionally, during the funeral ceremonies and consecutive future ones, the shaman instructs the individual to not return to harm living family members (MacDonald, 1996).

#### Iu Mien Funeral Ceremonies

According to fayes86 (2014), during the duration of the funeral there are several rules for family members of the deceased to abide by. These include: no copulation; avoiding oily foods as a mean to stay pure; no showering; avoiding entering other's homes besides family's; wearing white on one's head; not allowing the significant to attend the burial; banning family members from attending the funeral if that person's birthday is in the same month of the deceased; no sleeping during rituals; no calling for the deceased member for risk of their spirit being lost; no taking away food from the ceremonial house; and no pregnant women during the traditional rituals.

The Iu Mien funeral lasts 72 hours with the assistance of a main shaman and seven other men who helped share responsibilities. Within these 72 hours, the deceased is assisted in finding his or her level in the afterlife. Individuals who assist with the funeral rituals are logged into a notebook to ensure there is reciprocity of assistance in the future (fayes86, 2014). fayes86 (2014) related that funeral rituals are determined by men, and that they assist in making ceremonial money which is later burned to give wealth to the deceased. The deceased member is bathed by a loved one and ceremonial money is dipped to ensure that the deceased relative will be free from bad karma and can enter the afterlife in a pure form. The shaman is the first to leave to the burial site and after the coffin is released, the family is prohibited from looking back at the grave. The roles of women during a funeral are to assist in cooking and catering towards the men.

### Summary

The literature review provides a foundation for the research investigation. It is important to understand that Asian Americans as a group have been understudied in hospice and end-of-life care. Because of their lack of representation in the data, researchers have implied that there may be disparities in end-of-life care services for ethnic minorities (Connolly, Sampson, & Purandare, 2012; Bell et al., 2011). According to Enguidanos et al. (2013), Chinese Americans opted out on hospice care because they lacked knowledge about it. Additionally, due to cultural belief regarding end-of-life and care during the dying period, the use of hospice services may be underutilized.

Literature on the Iu Mien people is not only limited in regards to EOL care, but also overall cultural and demographic factors. This is reinforced by the lack of census data on this population. Consequently, this research study on Iu Mien perspectives on end-of-life decision-making is paramount. Hence, this study will enhance literature on the subject.

## CHAPTER III

### METHODOLOGY

Enguidanos et al. (2013) used a qualitative approach to learn about the perceptions of hospice care for older adults from Chinese American communities. This approach allowed the researchers to conduct in-depth interviews to better understand the views of the selected population regarding hospice care. The data was coded and provided overarching themes. Given the sensitivity of discussing about EOL, qualitative research may be used to capture direct, personal quotes that are reflective of an individual's experience and perspective (Patton, 1990; Woodgate, 2000). As with Enguidanos et al. (2013) study, the use of this methodology was the most appropriate choice to gather rich data from Iu Mien participants regarding death and dying and hospice care.

A qualitative approach, that includes the use of the in-depth interviews, leads to a greater understanding of the participant's experiences (Aldiabat & Le Navenec, 2011). The collection of qualitative data consists of comprehensive, open-ended interviews, direct observation, and written documents (Patton, 1990). The purpose of the qualitative approach is to analyze, interpret, and present patterns (Patton, 1990).

### Participants/Sampling

Patton (1990) discusses purposeful sampling as being used to identify the target population. For this study, purposeful sampling focused on a small sample to enhance and illuminate the discussion regarding EOL and hospice care from the perspective of the Iu Mien community. This approach is significant in providing "information-rich" cases (Patton, 1990, p. 169).

For this study, data were collected from eight female participants in Sacramento, California who attend an Iu Mien community senior center. Approximately 35- 40 older adults attend the community center on the two days it is open per week, Mondays and Wednesdays. The participants in this study were required to be 62 years of age or older and of Iu Mien descent. The participants were identified by two individuals from an Iu Mien community organization who held director and managing director positions. These individuals introduced this researcher to the prospective participants. After the introduction, snowball sampling was used to secure participants in the study.

Information on participant's age, gender, spoken languages, place of birth/origin, religion, number of children, location prior to immigrating to America, and the year of arrival to America was collected. The interviews were scheduled for each participant in person and during that time, the specific time and date to complete the interview was confirmed. The data collection occurred during a two-week period in December 2014.

The ages of the participants ranged from 64 years to 82, with an average of age of 71.2. Seven of the eight participants were born in Laos and one was born in China. The date of entry into the United States ranged from 1980 to 1987. This date correlates with the research regarding the timeframe that most Iu Mien individuals immigrated to the United States as refugees (Fitzpatrick, 2009; Macdonald, 1997). Seven of the participants indicated their religious orientation as Taoist, while one stated she was a Christian. The primary spoken language was Mien, though the participants were also versed in several other languages including English, Thai and Laotian. The number of children was an important demographic for this study due to the culture; the number of children of the participants ranged from two to eight with a mean of 4.3 (see Table 1).

Table 1

*Demographic Data of the Participants*

<b>Name</b>	<b>Age</b>	<b>Gender</b>	<b>Birthplace</b>	<b>Entry into the U.S.</b>	<b>Religion</b>	<b>Spoken Languages</b>	<b># of Children</b>
001	64	F	Laos	1987	Taoist	Mien, Laotian	2
002	80	F	Laos	1980	Taoist	Mien, Laotian	3
003	75	F	China	1986	Taoist	Mien, Laotian	4
004	62	F	Laos	1980	Taoist	Mien, Hmong, Laotian, Thai, English	5
005	66	F	Laos	1988	Taoist	Mien	6
006	72	F	Laos	1981	Christian	Mien, Laotian, Some English	8
007	72	F	Laos	1980	Taoist	Mien, Thai, Laotian	4
008	81	F	Laos	1984	Taoist	Mien, Laotian	3

### Instrument

This researcher created a questionnaire that consisted of a total of 20 quantitative and qualitative questions. Question 1-8 inquired about demographics. The remainder of the questions were open-ended and inquired about the participant's views of hospice and end-of-life decision-making. The questions explored the topics of death, community responses to death, end-of-life decision-making, knowledge about hospice services, and willingness to use hospice services. The research questions included the following:

- How is death viewed in your community?
- How does your community respond to a person who is dying?
- How does your community respond to the family of the person who is dying?
- What does death mean to you?
- What happens when a person becomes deceased in your family?
- Who makes the decision in your family and/or community about matters related to the rituals for the deceased? Why is this person the designated decision maker?
- Have you heard of Hospice?
- If so, what do you know about? [if not, researcher will provide a basic overview of philosophy and services]
- What are your thoughts about the idea of hospice [philosophy and services]?
- Do you know anyone who has received Hospice services?

- Would you use hospice services for yourself or for a family member? Why or why not?

The questions asked by the researcher were spoken in English and/or Mien, depending on the preference of the participant. The participants' names were coded to protect their identity. The codes ranged from Participant 001 to Participant 008.

*Data Collection.* The study was reviewed and approved by the Institutional Review Board (IRB) at California State University, Chico. A 45-day period was scheduled to collect the data. The researcher collected data at the community center over three days.

Before the initial interview, the researcher presented the purpose of the study and the method of data collection to the potential participant. Individuals interested in participating choose the date and time to complete the interview. The duration of the interviews was 30 – 45 minutes, including 15 minutes of orientation regarding the topic for each participant. During the orientation, the informed consent and consent to release information was explained to the participants to offer them an opportunity on whether or not they would like to release their names for the research. Per the request of all eight participants, the questions were asked in the Iu Mien language. They were audio recorded and then transcribed by the researcher.

#### Data Analysis

The data analysis process was influenced by grounded theory. Grounded theory is a systematic and flexible approach for collecting and analyzing data, using comparative methods to identify emerging analysis, and to develop theoretical concepts

and statements (Charmaz, 2007; Strauss & Corbin, 1997). This was the most appropriate theoretical approach for this study because it allowed for constant comparison of the data to ultimately identify patterns that lead to themes and subthemes. A component of the use of grounded theory includes the open coding of the transcripts, which later are then analyzed for themes (Enguidanos et al., 2013; Patton, 1990; Stocker & Close, 2013; Strauss & Corbin, 1998).

The interview of each participant was transcribed. A content analysis was used to analyze the content of the text (Kreuger & Neuman, 2006). Initial themes that emerged from the review of the transcripts were developed. The data was then analyzed through manual hand-coding for an assessment of frequency and patterns of themes and subthemes. The data was thoroughly hand-coded twice, to eliminate possible biases and provide an accurate interpretation of the data. The hand-coding method highlighted the commonalities and differential responses. Then, the responses were grouped together depending on their correspondence with other responses. Hand-coding allows for multiple individuals to provide important insight on content from the interviews (Patton, 1990). Additionally hand-coding allows the researcher to use "objective and systematic counting and recording procedures to produce a quantitative description of the symbolic content in a text" (Kreuger & Neuman, 2006, p. 305). A Microsoft spreadsheet was used to generate graphs to represent the demographic data.

## CHAPTER IV

### FINDINGS AND RESULTS

The findings and results will be discussed below by themes and subcategories. Perceptions of death will be reported first, followed by responses to death and dying, and then knowledge and acceptance of Hospice.

#### Perceptions of Death

The individual's view of the meaning of death and their own view of the community's view of death are explored. In addition, causes of death through the lenses of the individual and the Iu Mien community are discussed. Finally, the impact of religion and spirituality on perceptions of death are discussed.

#### Individual Self-Perception of Death

The participants were asked, "what does death mean to you?" The perception of dying among each of the participants varied. Two of the participants related that death was inevitable and a natural process of life. Participant 003 stated "we will all eventually die" and Participant 005 stated, "death is a normal process." Two other participants voiced their concerns and fears over dying. Participant 004 stated, "I worry a lot about death" and further stated, "no one wants to die." Participant 006 stated, "I see death as being very lonely. There is no one there for you after you die." When asked about the ability to foresee life after death and about life after death, three of the participants stated, "I don't know." Participant 007 stated "I can't see death. It's only a

story when people talk about descending into the sky. You can't see it." Participant 008 related, "I am unsure where we go after we leave this world. You can have a shaman do ceremonies for the deceased."

#### Individual's View of Causes of Death

The participants were first asked about their own view of death prior to asking about their perspective of how the Iu Mien community (culture) viewed death. Four of the participants mentioned "sickness" as a natural cause of death. For example, Participant 001 related her experience with her mother's illness stating, "she's been sick for a while...we captured a bird and did a ceremony to bring her luck. When I checked on her afterwards, she was shaking her head and then she became lifeless. That's what happened in my family and that's how I see death." She further related, "as for me I don't want to get sick and die. I want to just die peacefully in my sleep." Participant 004 stated "I don't want to get sick and pass away either." She related "I want my children to help me when I am dying." Participant 005 stated "I can get sick and become tired and I will say the saying 'it's not long before we die, it's too tiring'.

#### Participants' View of the Iu Mien Community's Perception of Death

The majority of the participants related that there were no discussions of death in the Iu Mien community. Six participants felt that it was a difficult topic to bring to discussion as evidenced by one participant stating, "we don't talk about it." Participant 002 stated, "It's not a topic we want to discuss" and "we don't talk about anything related

to it." Participant 004 reported, "if we are dying it is not a good feeling to talk about it" and "it's not a topic to speak lightly about."

#### Causes of Death Viewed by the Community

The participants were asked, "How is death viewed in your community?" Six participants view death among community members as "death by illness." Participant 001 related that death can be many things, "...some get sick for a while." Participant 002 discussed uncertainty about imminent death stating twice, "we will get sick or injured and die." Participant 003 stated, "we get sick. Those who don't get sick don't die, but if we are ill we start to lose our appetite and we eventually die." Participant 006 stated "we see people die...they greatly suffer from their illness before they die." She further stated "my husband suffered a lot before he died, he was nearly skin and bones." Participant 008 stated, "You get sick and if there is no cure, you pass away." Three out of the six of the participants who viewed death by illness also believed individuals passed away in their sleep.

A total of five participants believed the Iu Mien community perceives death as a time when one dies in his or her sleep from old age. Participant 001 also related "we see death by sleep." Participant 003 discussed "you can have a heart attack and die in your sleep." In addition, she stated, "there have been many recent deaths in the community where people passed away in their sleep." Participant 004 related, "We see people die in their sleep." Participant 004 compared death in the U.S. and her native land, Laos; she stated that "In America, there isn't a lot of illness, you grow old and die." She believed

that "in Laos people starved or died due to inaccessible medication." Participant 006 stated she perceived death as "we see people die in their sleep." Participant 007 stated, "death is inevitable."

### The Impact of Religion/Spirituality

Participant 005 pointed out that religious affiliation affected the discussions related to death. She related, "Taoist do not like to talk about death. The other day a lady brushed me off stating 'that's not something to talk about, why do you keep talking about death?' "Participant 008 stated "natural death cause are forbidden to talk about." However, two participants stated that there are certain situations that allow a discussion of death such as wrongful deaths or if the deceased individual had sinned in this world. Participant 007 stated, "if the dead person did not treat you well, you have to talk about it. It helps me feel better and other individuals who knew that person." Participant 008 reported, "if it is the fault of someone else, you can talk about it. For example, if you got a wrong injection that leads to death, you have every right to talk about it."

In contrast, five participants indicated that there were no problems discussing topics about death. Participant 003 stated, "no matter how much we talk about death, it doesn't impact whether we die or not." Participant 005 related, "We are able to talk about death and any topics related to it. I don't see any problems." Two of the participants indicated that death is not an acceptable topic. Participant 03 related it was inappropriate to talk about death to children due to superstitions of evil spirits harming children. The children's spirit is believed to be vulnerable to be "touched by a spirit and [then] the child

can fall ill." Religion was also viewed as another factor impacting discussions about death. Participant 006 believed that "Taoist people do not discuss death, but as a Christian, we can talk about death related topics."

### Responses to Death and Dying

The participants were asked questions related to the individual and community responses to death and dying. Each participant explored their perceptions regarding death and dying and provide insight about community responses as well.

#### Community's Response to Dying Individuals and Their Family Members

The participants were asked the following two questions: "how does your community respond to a person who is dying" and "how does your community respond to the family of the person who is dying?" The community response was described as assisting with ceremonies to determine the cause of illness and assisting the dying individual and their family member with funeral ceremonies. Participants spoke of "liu lay" and "jai jil" which are words to describe different ceremonies. "Jai jil" refers to helping an individual's spirit to cross a bridge and "liu lay" is the noun to plan ceremonies, more specifically funeral ceremonies. Participant 001 stated, "if we know someone is not well, we have to do a ceremony. Sometimes this can help them get better. However, if it's their time to leave this world, the ceremony will not prolong the life." Similarly participant 003 stated "we can have shamans try to do a ceremony to determine the cause and provide a remedy."

As for community response to the family of the dying individuals, Participant 003 stated, "we have to go and help them with preparing for the funeral. The family members must 'tei la fiemme' which is the traditional, proper way to send someone to the afterlife. We help family members prepare for that." Participant 005 stated, "We would help find a shaman to perform the funeral ceremony. If they died, we have to 'liu lay' and then proceed with the funeral." Participant 007 stated, "you can have a ceremony and try to cure the person to get rid of bad spirits." Five of the participants also spoke of the community relaying to the family the need to find appropriate dates for the ceremony and assisting them in finding a shaman to perform the ceremonies.

Other community responses to an individual dying and their family members included providing social and emotional support. Four of the participants stated that community members visit the dying individual and their family members to ensure that the dying individual's "heart is content and free from worry," and "to make sure the person is comfortable." Two of the four participants believed that community members had "to be sympathetic" and "consoling" to the family members of the dying/deceased individual as well. Participant 004 states "the community will console family members by telling them that pain is normal, they might be able to get well, and don't worry too much about it."

One participant believed community members would help establish harmony in the dying person's household and prevent the family members from arguing.

Participant 007 stated "we must make sure the family members don't get 'ho chi' (fighting spirits)." This reportedly created less of a worry for the deceased individual.

#### Family Response to Death

The participants related that family members included immediate and extended family members. All eight of the participants were in agreement on how a family in the Iu Mien community responds to a family member's death. They related that when an individual becomes deceased, the family members need to provide physical assistance with the funeral ceremonies. Five participants noted that family members must help prepare and cook meals for everyone who will be in attendance at the funeral ceremonies. Participant 001 stated, "whether the deceased person is Christian or not, you have to go help with the ceremony." One individual mentioned that donated money and food/drinks are recorded in a notebook by family members of the deceased so that they may repay the community in the future.

Preparing the body and burial. Several participants emphasized the importance of assuring that the deceased individual will have a comfortable afterlife through a proper funeral. According to Participant 002, the ceremonies are intended "to assure that the [deceased] person is living comfortably in the afterlife." Additionally, Participant 003 stated family members must prepare the deceased with proper burial attire and materials such as "you clothe them in proper burial clothes, head wrap, socks, and shoes." She further stated that a family member must make a pillow to prevent the deceased from

looking at his/her feet because if this does not occur, "the spirit of the deceased cannot passed into the afterlife."

Six participants stated that appointed family members are responsible for the funeral preparations. Family members are responsible for finding a shaman to perform the traditional rituals in the funeral ceremony and to select an appropriate burial date for the deceased. Participant 004 stated that family members who live with the deceased are responsible for making funeral arrangements. For her own death, she stated, "the one who lives with me is head of the household and it is their responsibility to find a shaman and make arrangements for the funeral." Participant 006 stated, "Anyone in your family who is intelligent and understand proper burial ceremonies will help make the funeral arrangements." Similarly, participant 007 named her "brother and sister" as designated responsible parties for her death and she would be responsible for theirs since they are more familiar with the traditional burial ceremonies. Participant 008 stated, "If I am not well, my children will help plan. My daughter would be able to discuss about my funeral since she is my biological daughter. She is responsible for those matters."

Although the majority of the participants named family members responsible for the funeral arrangements, there was no consensus on whether there was a designated individual to assume complete responsibility. Two participants expressed concern that the "younger generation" lacked knowledge on what a proper burial ceremony entails and would need to seek elders in the community to assist with the funeral ceremonies. Participant 003 and Participant 005 related that family members should find "anyone that

is aware of the old traditional burial ceremony" to assist with the funeral ceremony. Participant 003 further stated, "My kids are old, but I don't think they are capable of carrying out the ceremonies. They haven't seen much [proper funerals], so they wouldn't know about what a proper burial would include." She also stated, "When community members learn of a death and realize that there is no one to make decisions about a proper burial, they will step in and provide assistance." Participant 005 stated "you have to go and please for people to come assist with the funeral preparations and "liu lay" (funeral planning).

### Hospice

The participants were asked about their views of hospice philosophy, their knowledge of hospice, utilization of hospice services, and their receptiveness to hospice services.

#### Lack of Knowledge of Hospice

All eight of the participants related having no knowledge of hospice and its services. One participant specifically stated that the research interview was the first time she had heard the word. Seven participants cited their unfamiliarity with hospice services as a result of their lack of fluency with the English language. Participant 002 stated "Hospice? It's an English word. I am unfamiliar with it."

#### Underutilization of Hospice in the Community

All eight participants stated initially that they did not know anyone in their community who had received hospice services. They requested detailed explanations of

hospice services due to the unfamiliar nature. Following this information, two of the participants indicated knowing someone who may have received hospice care. For example, Participant 003 stated, "I have a neighbor who was ill for a long time. He came home from the hospital and there were professionals who came to see him. Maybe it was people from a hospice program?" In addition, Participant 007 stated, "I have heard of people using hospice before. There are people who have homes who get sick, but are not dead and are fatigued and very ill, but can't do anything."

#### Positive Attitudes of Hospice Philosophy

All eight of the participants related a positive perception of hospice following a brief description of the services provided. Following this, the participants seemed to view hospice as a service to assist individuals who are ill and provide the family support. For example, Participant 001 stated, "I think a lot of people will like this program. If they know about the program, they will like it." Participant 003 stated "if you are immobile and unresponsive, but cannot die...hospice would be good to assist us in our care. It would be wonderful to just have someone bring you to the bathroom and change your Depends." Participant 004 related, "I like hospice a lot. If there is someone to come help you, that's great!" Additionally, Participant 005 stated, "I like the hospice program because you can't predict the future. It'll be nice to have support in the future when you need it the most." She further stated, "If our children are afraid of ghosts or looking at the ill family member, it will be good to have outside help [hospice services] to assist in bathing and clothing the ill family member."

Four of the participants expressed concern about needed money for end-of-life care and related appreciation for Medicare to cover the expenses of qualified patients.

Participant 003 stated, "us Mien people, we need as much support as we can get."

Participant 006 stated, "I think hospice is great. We don't have to give money."

#### Willingness to Use Hospice Services

After receiving a brief explanation of hospice services, seven of participants expressed interest in using hospice services in the future. Participant 001 stated, "if I have the opportunity to use hospice, I will use it." Participant 004 related, "I would like to use hospice when I am ill or when a family member is ill." In addition, four of the participants found the benefits to be significant in influencing their interest in using the services. For example, Participant 006 stated, "I would like to use hospice services. I like what you told me about Hospice. There are many benefits with it." Those benefits as cited by the participants are "providing care" and "support" in the home. Participant 007 related, "I would like someone to come bathe me, clothe me, and administer medication" and Participant 008 stated, "If we are not well and they can come and provide medication."

The participants did not indicate concern that hospice services would quicken death. For example, Participant 003 stated, "I don't think hospice will make me die faster." She further stated, "It's more like if they come and provide care in my home they might leave if I get better. If they come and we still die, then that's that."

### Uncertainty in Using Hospice Services

During the initial discussion of hospice, two participants related uncertainty regarding use of services. However, this seemed related to lack of knowledge as following a discussion of the services. For example, Participant 002 initially stated, "I can't determine right now whether I want to use Hospice or not. I don't know much about it." However, after greater explanation, she stated, "Is that what hospice is? When you are sick they come and provide care? If this is the case, I like it." One participant remained uncertain as to whether she would use hospice in the future.

### Discussion

Due to the sensitivity of the subject matter, personal communications with Iu Mien elders and scholars prior to the data collection revealed that the topic of dying, death, and EOL care might not be well-received by potential participants. The review of the literature reveal extremely limited study in this area with the Iu Mien community and thus, this researcher anticipated not only potential challenges due to a potential taboo regarding discussing death and dying, but also due to unfamiliarity with hospice as a concept and services. It is important to note that 75% of the participants at the community center appeared anxious during the beginning stages of research. Six of the participants expressed concern of "not knowing how to respond or what to say to the questions." However, these six participants agreed to partake in the interview after seeing other community members complete the interviews. This seemed to demystify the process and reassure that the interview would not be stressful.

### Individual and Communities' Perception of Death and Dying

Each participant seemed to experience difficulty describing her own perception of death and its meaning to her. To this researcher it seemed unclear if the responses to questions regarding individual perceptions of death were a result of the lack of conversation and openness about death and dying in Iu Mien community or to individual variations. The literature presented in this study indicated that EOL decision-making and death are not openly discussed with patients and their family members in Asian American families (Colclough & Young, 2007; Jang et al., 2010; Kwak & Salmon, 2007). The responses by the eight participants revealed contrasting perceptions. Five of the participants conveyed a lack of conversation about death in the community, whereas the remaining three participants related that conversations about death were acceptable. However, two of the three participants who expressed community openness to hospice services stated there were some exceptions that prohibited the discussion of death. Therefore due to the exceptions, it would appear that seven participants did not believe discussion related to death were permitted in the community.

The exceptions described by the participants involved spirits entering into this world and harming an individual. Similar to the Iu Mien, Gerdner et al. (2007) discussed that the Hmong believed discussions of death would open the gate for evil spirits to enter the human world. The lack of discussion of death for the individual was also a result of "worry" or "fear." One participant believed talking about death would hasten death for an individual that was dying. She stated, "it wasn't a good feeling to talk about your death or

anyone else's death." Thus, the lack of communication about this topic seemed to influence the uncertainty surrounding the individual's perception of death and dying. The only participant who expressed no exceptions regarding the discussion of death was the participant who related a Christian faith. She believed Christians can talk about death, but individuals of Taoist beliefs did not.

As a result of the response in this area, it is important to understand that the Iu Mien community may not have open conversations about dying or EOL care. The responses indicate that the Iu Mien community has an important influence on an individual's perception of death and dying. There may be varying levels of comfort in discussing death and dying. Overall, the topic of dying and EOL care is not normalized and would affect the utilization of hospice services from the Iu Mien community. For hospice care providers, having knowledge about the lack of discussion of death and dying in the Iu Mien community can help improve quality care and provide insight into factors dictating an individual's choice about hospice services.

#### Lack of Knowledge of Hospice Care

The literature indicated that the lack of knowledge of hospice services is prevalent in many communities (Doorenbos & Schim, 2004; Friedman et al., 2002; Harber, 1999; Reese & Beckwith, 2014). All eight of the participants indicated that they did not know about hospice services. Hospice may be an underutilized service as there is not enough educational outreach regarding hospice services to underserved communities. Additionally, there is a lack of culturally competent staff (Harber, 1999). In light of these

two variables, the initial response by the participants indicating little knowledge of hospice services might be a reflection of the lack of funding available to provide educational outreach to diverse communities as well as staff who are familiar with the Iu Mien community (Reese & Beckwith, 2014). The lack of educational outreach to the Iu Mien community could be attributed to limited production of language-friendly brochures and/or collaborating with community leaders to recruit enrollment in the Iu Mien community.

As a result of the response from the participants, it is beneficial to understand barriers impacting the Iu Mien community's access to hospice services. This will improve methods to increase hospice enrollment in this community through potentially creating more language-friendly brochures and hiring more culturally competent staff (Harber, 1999; Reese & Beckwith, 2014). Specifically, since the Iu Mien have a smaller community with unique spiritual and religious beliefs, it is vital to learn about how to better serve their communities. Performing proper funeral ceremonies was a running theme for all eight of the participants and thus must be understood in order to provide quality of care.

The literature revealed that proper funeral ceremonies performed with a shaman are a part of the Iu Mien Taoist belief (MacDonald, 1996). This is an important aspect and should be considered by hospice workers when working with Iu Mien patients. For a hospice program to become culturally competent, the teams would need to embrace and validate the ceremonies; this would fulfill the hospice goal of providing patients with

a quality of life that is reflective of their culture (Doorenbos & Schim, 2004; Harber, 1999; Reese & Beckwith, 2014). This would include honoring a family's wishes of when to decide to make EOL decisions and allowing the family to proceed with their traditional funeral planning following a death (Colclough & Young, 2007, Kwak & Salmon, 2007). Therefore, being more culturally competent would increase the utilization of hospice services and allow hospices to accomplish their beliefs of how to assist individuals with dignity and respect (NHPCO, 2012).

#### Positive Attitudes Towards Hospice: Revisited

Upon receiving an detailed explanation of the services provided by hospice, seven of the participants expressed interest in using hospice services in the future for themselves or family members. Cagle et al. (2014) found that older adults had more favorable attitudes about the philosophy of hospice care compared to other age groups. Upon learning about the program, the participants seemed to have a similar response as to those in the study by Cagle et al. (2014). They indicated a preference toward receiving care in the safety and comfort of their home versus other settings. For example, Participant 002 had expressed uncertainty initially about whether or not to use hospice services, but ultimately changed her mind to wanting to use it. Thus, education regarding hospice care seemed to increase the possibility of utilizing the service or sharing the information about the services with others.

#### Family Responsibility

The interviews revealed varied responses regarding who in the family would assist with the care of the dying or would be responsible for EOL care decisions. The reason for uncertainty as to who would be designated could be due to a multitude of factors. According to McLaughlin & Braun (1998), in collectivistic cultures the goals of the group are more important than that of the individual. Many decisions are to be made by the family, including children, and groups. In the case with the Iu Mien participants, six participants expressed EOL decision-making would fall under the responsibility of family members.

In this study, six of the eight participants chose family members as responsible parties for EOL decision-making. In the Iu Mien community, family involvement is important in the death and dying process (Ying & Chao, 1996). Ngo-Metzger et al. (2009) discussed that filial piety can influence whether or not family members would allow their loved ones to choose hospice instead of curative therapy. They related that "filial piety is the moral obligation of children to care for elderly parents" (Ngo-Metzger et al., 2009, p. 5). In the Iu Mien culture, filial piety is emphasized since birth and can impact whether an adult child would approve or disapprove hospice services for their elderly parent. Six of the participants agreed that intermediate family members should take responsibility with EOL care, whereas two participants believed it should fall on community members with more knowledge of EOL care. Thus, community support is common among this population.

The two participants expressed concern over their children's lack of knowledge on the traditional burial ceremonies. They alluded to intergenerational differences that might create conflict towards the end-of-life. Mondia, Hichenberg, Kerr, Eisenberg, and Kissane (2012) found that the differences in lifestyle between immigrant parents and their acculturated children in the U.S. decreased cohesion between family members. Children who are more acculturated would take on more traditions of their host country, whereas the immigrant parent would adhere to traditions from their native country (Mondia et al., 2012). This is significant in influencing the designated individuals to make EOL decisions in the Iu Mien family household due to the large number of Mien children born in the U.S. Therefore, it is paramount to understand the intergenerational conflict can lead to better understanding of preferences of Iu Mien elders.

#### Summary

Since the majority of participants deemed "family members" as responsible individuals for EOL care and planning and facilitating funeral ceremonies, there seemed to be a high chance that family members would have a significant input about whether to choose hospice services. Hospice philosophy involves meeting the needs of the family members as well as their communities, which can fit well with the collectivistic community's ideals (Doorenbos & Schim, 2004). Participant 002 stated that her children would be responsible for making end-of-life decision-making, including the utilization of hospice services.

As a result of the response, it may be beneficial to include family members in every process of EOL decision-making to improve the enrollment rate of Iu Mien community in hospice. The educational outreach should target Iu Mien elders and their family members. There is a higher chance for an Iu Mien elder to choose hospice services if there are approvals from their family members. Therefore, understanding the role of family members is important to increasing hospice access for the Iu Mien community.

## CHAPTER V

### CONCLUSIONS AND RECOMMENDATIONS

#### Conclusion

At the beginning stages of the research, there were forewarning messages through personal communications with elders and scholars in the Iu Mien community regarding the high chance of receiving a lack of responsiveness from the Iu Mien community regarding EOL decision-making. This is a sensitive issue and not normalized as a topic of discussion. However, the participants in this study expressed interest in having conversations regarding EOL decision-making. Seven of the participants expressed a desire to have more knowledge about their options instead of waiting until they are unable to do take part in decision making.

Many Iu Mien members understand that a proper traditional burial can be expensive. Seven of the participants related that a proper traditional burial can be expensive. The Medicare-funded hospice services might alleviate some financial concerns communicated by the participants, as hospice would cover medication expenses, doctor in-home visitations, as well as home health care assistance. Additionally, with a cultural understanding of the Iu Mien community, hospice team members would have knowledge to validate and support ceremonial practices. This would directly reflect the hospice philosophy of providing dignity and respect for the patient and his or her family members.

Hiring culturally sensitive staff members in hospice agencies would be a factor in increasing the likelihood of the utilization of hospice services by ethnic minorities. Many studies have concluded that the formula to increasing access to hospice services includes having more staff trained in cultural competency (Doorenbos & Schim, 2004; Harber, 1999; Reese & Beckwith, 2014). This directly influences the educational outreach to minority communities. The literature also suggests the importance of collaboration with community leaders and providing educational outreach for hospice services (Harber, 1999; Reese & Beckwith, 2014). This was echoed by the participants who encouraged further presentations of educational outreach to various community center sites similar to the one they attended. Thus, the NASW Code of Ethics values of cultural competency and research serve as a guiding force to increase cultural knowledge and practice skills and behaviors, as well as increase the literature in this area of study.

#### Recommendations for Further Research

Future research on this topic would benefit from a larger sample size that would include both males and females. This would provide greater data to guide understanding of the differences regarding Iu Mien perspectives on end-of-life decision-making. Recruiting participants from different areas in the U.S. would provide an even greater wealth of knowledge.

It would also be beneficial to include shamans in future research. This would further clarify practices during the end-of-life and provide more detailed accounts of

ceremonial practices. Additionally, interviewing Iu Mien family members who received hospice services would also provide more insight about Iu Mien experiences using hospice services.

To enter a specific culture, it is important to have access through a gatekeeper who will introduce the researcher to the community. Although this occurred for this researcher, it seemed that greater time with the introductory process might have decreased the anxiety of potential participants. A longer and more in-depth orientation about the study might have encouraged more individuals to participate. During the recruitment stage, some potential participants declined because they were uncertain of what questions would be asked. They were concerned about their responses, seeming to focus on if they would be correct or helpful. An open discussion with a few participants in a group scheduled meeting, such a focus group, might have increased participation. Since the Iu Mien is a collectivist community, the topic of EOL may have been better conceived in a group setting.

Although the sample size was small, and the research was conducted in one specific area, the data revealed the need for continued research. Increased understanding of the cultural views of the Iu Mien community regarding end-of-life decision-making and hospice care will enhance the quality of care provided professionals.

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## APPENDIX A

**Consent for Release of Information**  
Information to Consider Before Taking Part in the Study  
IRB Study #:

I am a Masters of Social Work student at California State University, Chico. I am conducting a research study for my master's thesis and I am asking you to take part in the study. The research study is called: Perceptions of End-of-Life Decision-Making and Hospice Care of Iu Mien Elders

**Purpose**

The purpose of this study is to assess the views of end-of-life decision-making and the view and knowledge of hospice care by elders (65 years +) in the Iu Mien community.

- The goal of the study is to provide greater education of the Iu Mien community regarding the services provided by Hospice.
- The results are also intended to provide culture-specific information for educators and social work practitioners to become more culturally sensitive regarding the Iu Mien community and views of death and dying and hospice care.
- The results will be shared with educational professional and social work practitioners through a written narrative providing all the details of the thesis, a thesis defense presentation, and possible conference presentations and publications.

**Duration of Research**

The survey portion of this research will be conducted between December 20, 2014 – January 15, 2015. The survey will take approximately 30 minutes- one hours to complete. Your answers will be analyzed without your identifying information. The AtlasTi computer program will qualitative analysis.

The survey session will be audio-taped and transcribed for the analysis of the information. Once the project study is complete, the audio-tape will be kept in a locked file cabinet in the CSU, Chico School of Social Work office for one-calendar year. At that time, the audio-tape will be destroyed.

For your participation, you will be provided with \$10.

**Release of Information**

By signing below, you acknowledge that you will be consenting to releasing your age, sex, ethnicity, spoken language(s), marital status, place/birth of origin, date when you came to the United States, and the number of your children, Your name will not be used in this study, unless you sign that you consent to the use of your name (additional consent at the bottom of this document). You will be identified by a code/number.

### **Risks or Discomfort**

I may be asking you to share with me your view of death, care of the dying in the Iu Mien community, and view of Hospice. Your participation in this project is voluntary and you may withdraw from the study at any time. You may refuse to answer any questions, skip questions, and may stop participating at any time. Your refusal to answer a question or to withdraw from participation will have no repercussions.

If you experience discomfort following the interview, the primary investigator will discuss with you any questions or concerns you may be experiencing. If you need further assistance, the primary investigator will refer you to the family member of your choice, an elder, or a community service if you desire. Information on community support services will be provided as well if you wish to seek emotional support at a later date.

### **Benefits**

The potential benefits for participating in this study is that you will provide information on your view of death and dying, and hospice care that will be used to educate the Iu Mien community, teachers, and social workers about the Iu Mien culture. This information will assist in increasing understanding and in turn, more culturally competent services.

### **Questions, Concerns, Complaints**

Should you have any questions or concerns please contact the primary investigator, Gain Saetern, gsaetern1@mail.csuchico.edu or via phone 916-531-1401.

By signing below you are agree to the follow information:

- I have fully read the above information.
- I understand that I am being asked to participate in a research project that is to assess the views of end-of-life decision-making and hospice care by Iu Mien elders.
- I understand the risks and benefits, and I freely give my consent to participate
- I release my information in the research project outlined in this form, under the conditions indicated in it.

Participant Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Investigator's Signature(s): \_\_\_\_\_ Date: \_\_\_\_\_

I \_\_\_\_\_ consent for my given name to be used in the research study  
(name)

reports that include a thesis and possible presentations and/or publications.

Participant Signature \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX B

## Survey of End-of-Life Decision-Making and Hospice Care

### Demographics

1. Age  65-70     71-75     76-80     81-85     85<sup>+</sup>
  
2. Gender     Male     Female
  
3. Spoken Language(s) : \_\_\_\_\_
  
4. Place of birth: \_\_\_\_\_
  
5. Religion: \_\_\_\_\_
  
6. # children: \_\_\_\_\_
  
7. Location prior to Arrival in America: \_\_\_\_\_
  
8. Year of arrival to America: \_\_\_\_\_
  
9. How is death viewed in your community?
  
10. How does your community respond to a person who is dying?
  
11. How does your community respond to the family of the person who is dying?
  
12. What does death mean to you?
  
13. What happens when a person becomes deceased in your family?
  
14. Who makes the decision in your family and/or community about matters related to the rituals for the deceased? Why is this person the designated decision maker?
  
15. Have you heard of Hospice?
  
16. If so, what do you know about? [if not, researcher will provide a basic overview of philosophy and services]

According to the National Hospice and Palliative Care Organization (2014), hospice is a state funded Medicare program which provides pain free and comfort care for individuals diagnosed with a 6 months prognosis or less. In hospice, there is a team of health professionals such as: doctors, nurses, social workers, spiritual support, home health aides, and home maker services; attending to the needs of the patients during the final latter in life. Additionally, support for the family is provided one year after the loved ones death (bereavement services)

17. What are your thoughts about the idea of hospice [philosophy and services]?
18. Do you know anyone who has received Hospice services?
19. Would you use hospice services for yourself or for a family member? Why or why not?
20. What suggestions do you have for us to help more people in the Iu Mien community learn about Hospice Services?

## APPENDIX C



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HUMAN SUBJECTS IN REVIEW COMMITTEE  
Post Data Collection Questionnaire

Under Federal law relating to the protection of Human Subjects, this report is to be completed by each Principal Investigator at the end of data collection.

Please return to: Marsha Osborne, HSRC Assistant  
Office of Graduate Studies  
Student Services Center (SSC), Room 460  
CSU, Chico  
Chico, CA 95929-0875

Or Fax to: Marsha Osborne, 530-898-3342

Name: Gari Saetern \_\_\_\_\_ Chico State Portal ID#006439148 \_\_\_\_\_

Phone(s) 916-531-1401 \_\_\_\_\_ Email: gsactern1@mail.csuchico.edu \_\_\_\_\_

Faculty Advisor name (if student): Susan Roll \_\_\_\_\_ Phone (530) 898-4275 \_\_\_\_\_

College/Department: College of Behavioral and Social Sciences

Title of Project: The Perceptions of End-of-Life Decision-Making and Hospice Care of Lu Mien Elders

Date application was approved (mo/yr.): 10/2014 Date collection complete (mo/yr.): 12/2014

How many subjects were recruited? 8 How many subjects actually completed the project? 8

\*HARM: Did subjects have severe reactions or extreme emotional response? No

If yes, please attach a detailed explanation: \_\_\_\_\_

Your signature: *[Signature]* \_\_\_\_\_ Date: 04/03/15 \_\_\_\_\_

\*Final clearance will not be granted without a complete answer to this question.

Approved by: *[Signature]* \_\_\_\_\_ Date: 4/8/15 \_\_\_\_\_  
John Mahoney, Chair

\*\*\*\*\*

VERY IMPORTANT: If you will or have used this research in your project or thesis you are required to provide a copy of this form (with John Mahoney's signature in place) to your graduate committee.

Do you want a photo copy of this form emailed to you? yes  
If yes, provide email address: gsactern1@mail.csuchico.edu

4/8/15 ✓ in 40 min