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PROVIDING CULTURALLY COMPETENT ELDERCARE FOR ASIAN AMERICANS

by Britney V Ngo

A thesis submitted to the faculty of The University of Mississippi in partial fulfillment of the requirements of the Sally McDonnell Barksdale Honors College.

Oxford May 2022

Approved by

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ABSTRACT

BRITNEY V NGO: Providing Culturally Competent Eldercare for Asian Americans (Under the direction of Dr. Sarah Moses)

As the Asian American elderly population continues to grow, it is important to acknowledge cultural factors that may impact their behavior, attitudes, preferences, and decisions in the context of eldercare. Cultural competency acknowledges and considers these factors while providing care that includes biophysical factors of healthcare as well as non-medical dimensions of care such as language and culture.

This thesis seeks to address the applications of providing culturally competent eldercare to Asian Americans and offer future recommendations to care settings that have limited resources by utilizing a multidisciplinary review of literature accompanied by interviews with representatives from On Lok, a geriatric clinic that cares specifically for aging Asian American patients and the Office of Preventative Health and Health Equity within the Mississippi State Department of Health to analyze and assess the demographics of aging Asian Americans, the need for culturally competent care, cultural factors to consider in the care of aging Asian Americans, and structures within our society that exist today to provide culturally competent long-term and clinical eldercare for Asian Americans.

By evaluating existing models and methods of culturally competent eldercare for Asian Americans such as ethnospecific long-term care facilities, ethnospecific clinics & culturally competent providers, interpreting services, and family caregiving support & home health services, key cultural factors to consider within eldercare of Asian American population were identified: filial piety and familial decision making, alternative medicine, influence of faith and

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spirituality, lower rates of advance directives compared to whites, somatic presentation of mental health, Eastern diets, and risk factors & lower rates of preventative screening. Finally, recommendations when providing culturally competent eldercare for Asian Americans in care settings with limited resources were also determined: education for healthcare providers & professionals, individualized care through communication, incorporation of caregivers and family members, accessible advance directives, community engagement, and representation in research.

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Introduction

When introduced to eldercare and end-of-life care during Dr. Sarah Moses' Biomedical Ethics course and our analysis of Atul Gawande's *Being Mortal*, I became aware of the many complexities that caring for the aging comes along with. As an Asian American woman with aging relatives and relatives who have lived in long-term care facilities, I became captivated by the intersection of culture and eldercare.

Shortly after, I began working as a medical assistant in an urgent care and family medicine clinic in Oxford, Mississippi where we care for a small population of Cantonese-speaking Chinese American patients and volunteering at the Jackson Free Clinic. Within these clinical settings, I have been able to have a first-hand look at a few of the many challenges that exist when providing culturally competent care from language barriers to hesitancy to Western medicine.

One morning, a nurse that I worked with, Lesley, asked me if I could explain to a Chinese woman that her husband had diabetes. Lesley tried to explain the lab results to her over the phone as we routinely did; however, this conversation left her even more confused as English was not her native language. Her husband's lab results had just come back from his first doctor's visit in 7 years—his A1c was 7.1. The normal range for A1c levels is between 4 and 5.6, and levels of 6.5 or higher indicate that you have diabetes (Dansinger). As I waited for his wife to arrive, I quickly looked up medical terms with the phonetic Cantonese pronunciations online. I repeated 糖尿病 (tong4 niu6 beng6), the word for diabetes in Cantonese, in my head over and over so that I wouldn't forget how to say it. When she arrived, I explained her husband's lab results to her. I told her he had diabetes, we sent him metformin to their pharmacy, and he would

have to adjust his diet and monitor his blood sugar. She was shocked, and she had many follow up questions. She, Lesley, and I went back and forth to communicate the information she needed for her husband.¹ After she left, I felt unsettled. I questioned whether I translated the information well enough for her to understand through my limited Cantonese proficiency and to go on to explain the information to her husband. I thought of the times my family members have asked my sister, a pharmacist, to explain to them why their providers prescribed certain medications to them because they didn't understand when their providers explained it to them. I wondered what my clinic would have done if they didn't have a Cantonese speaking medical assistant. Would she have gone without the adequate information to care for her husband? How often does this happen in other clinics and healthcare settings? How did this situation fit into a larger problem? As an aspiring physician assistant interested in geriatric and primary care, the observations I have made as a medical assistant combined with my interest in eldercare and end-of-life care urged me to explore what structures exist today to bridge the gap for aging Asian American patients, how those strategies are implemented, and how we can learn from and build off of them so that I, along with others, can strive to provide more accessible and appropriate care for aging Asian Americans patients.

Eldercare, also referred to as senior care, is a broad term encompassing care designed to meet the needs of aging persons at various stages. Aging itself does not require eldercare, but instead declines in health associated with aging prompt the need for eldercare. Generally, eldercare becomes necessary when an aging person begins to experience physical, cognitive, or even emotional difficulty with their activities of daily living (ADLs) safely and independently

¹ The names used in the narratives within this thesis have been changed, and there are no identifying characteristics stated to protect the privacy of the individuals that they refer to.

(Senior Care). While eldercare will inevitably include end-of-life care, it is not restricted to end-of-life care. According to Phyllis R. Coolen, DNP, community health and hospice clinician, cultural competency is defined as the "ongoing journey of commitment and active engagement through the process of cultural awareness, knowledge, skills, collaboration, and encounter." As the Asian American population ages 65 and older continues to grow, it is important to acknowledge cultural factors that may impact an aging Asian American patient's behavior, attitudes, preferences, and decisions in the context of eldercare. Cultural competency sets the framework that eldercare fits within as the influences of Asian American culture that impact eldercare and eventually end-of-life care are boundless: filial piety and familial decision making, alternative medicine, influence of faith and spirituality, lower rates of advance directives compared to whites, somatic presentation of mental health, Eastern diets, and risk factors & lower rates of preventative screening. Culturally competent eldercare is especially important for patients with dementia as they often revert back to their early memories such as childhood and speaking their first language (Bowden). It is imperative to engage with the cultural aspects of the patient's self as it morally "holds them in their identity" (Lindemann 417). Through her vignette about her grandmother, Lindemann claims that family members have the responsibility to hold on to their loved ones' identity for him or her through "acts, experiences, relationships, and commitments to characterize a person" (417).

The Asian American population ages 65 and older was 2.49 million in 2017, and is projected to grow to 7.9 million by 2060 (Administration on Aging 2). Asian Americans account for 102% of the 115% projected increase amongst racial and ethnic minority populations age 65 and older within the United States (Administration on Aging 5). This immense projected growth

in the aging Asian American population demonstrates the need for culturally competent eldercare delivered through primary care settings, long-term care facilities, interpreting services, home-based care, and caregiving support. Culturally competent care is not only relevant now as seen through the number of aging Asian Americans in the United States, but it will continue to be imperative for decades. The number of aging Asian Americans will continue to grow. While there may not be as great of a need for linguistically-specific care in the younger generation of Asian Americans when they age as they assimilate to the American culture and speak English more fluently, the need for culturally competent care and knowledge of the medical conditions that Asian Americans are at risk for remains. This relevancy and cruciality can be seen through the continuation of immigration and the presence of ethnic neighborhoods and communities in which families and individuals do not assimilate at the same rate as others.

During my exploration of existing forms of culturally competent care, I found that culturally competent eldercare for Asian Americans exists in many forms including ethnospecific long-term care facilities, ethnospecific clinics & culturally competent providers, interpreting services, and family caregiving support & home health services. The care these structures and methods provide is different in their delivery but they each acknowledge that caring for the Asian American demographic requires efforts in cultural literacy and creativity in order to provide culturally and linguistically specific care to preserve the identity, well-being, and health of care recipients (Vega). The main considerations that healthcare facilities and providers take when providing culturally competent care are as follows: interpreting services, familial decision making, traditional medicine, cultural food and activities, religious beliefs, and knowledge of prevalent illnesses in Asian American patients. By becoming aware of these factors, healthcare

institutions and providers can then work to develop initiatives to improve healthcare for the aging Asian American population and to educate medical providers and professionals on the presence of such factors. Healthcare in this context refers not only to the biophysical factors of healthcare, but also the non-medical dimensions of care such as language and culture. Many of these models of culturally competent care are available in states with sizable Asian American populations. However, ethnospecific nursing homes are not feasible in many smaller cities as there is not enough demand to adequately fund them. Even in cities with ethnospecific nursing homes, many have extensive waitlists that take years to get off of (Bowden). Likewise, in these smaller cities, multilingual PCPs and culturally competent home health services may not be available. As the number of elderly Asian Americans and the Asian American long-term care population increases, my interest in ways that culturally competent eldercare can be implemented in traditional settings such as traditional long-term care facilities and clinics grew (Feng 5; Vega). Thus, the central question of my thesis is: what aspects of culturally competent care are most important for improving quality of life for Asian American elderly, and how can those "best practices" be integrated into care settings with limited resources?

In order to identify these "best practices", I explored the existing forms of culturally competent eldercare for Asian Americans through literature from various disciplines in relation to my topic including but not limited to medical science, gerontology, ethnogeriatrics, bioethics, healthcare institutions, sociology, and biostatistics. This literature also varies in methodology, including statistical research, surveys, ethnographic interviews, articles detailing personal experiences, and cultural competency guides. By integrating information from multiple perspectives and disciplines related to the Asian American population, culturally competent care,

and eldercare, I aim to approach my research question with consideration of diverse angles so that I can provide an answer that is well informed and representative of the multitude of experiences that aging Asian Americans have.

Alongside the literature related to my research questions, I sought out qualitative, real-life implementations to juxtapose with and to bring depth to my research. I analyzed the way culturally competent considerations are acknowledged clinically through interviews with Dr. Alice Mao, a geriatrician at On Lok in San Jose, California, a clinic that cares specifically for aging Asian American patients and Dr. Nikki Johnson, the Director of Special Projects in the Office of Preventative Health and Health Equity at the Mississippi State Department of Health. Through these interviews, I learned of ways in which providers, healthcare professionals, and government agencies can acknowledge patients' culture and clinical issues when caring for them. These interviews provided insight on how two distinct settings of interest utilize methods of cultural competency to address cultural needs and considerations in the care of aging Asian Americans. In my interview with Dr. Mao, I asked her questions pertaining to the approach that she takes when providing culturally competent eldercare for her patients (see Appendix A). I was able to recognize how occurrences within these settings of interest fit within broader studies in the literature I engaged in. While my research findings are based on the literature that I draw from, these interviews serve to accompany and bring life to my findings. Ultimately, I sought to learn what makes culturally competent care most effective and feasible in real world applications.

My field visits to Aegis Gardens in Fremont, California, and On Lok PACE Center in San Jose, California were scheduled to occur in January 2022. Due to the surge of COVID-19 cases

due to the omicron variant during this time, I was unfortunately unable to enter both facilities and thus unable to shadow healthcare providers within these sites. As a result, I observed both facilities from the outside, took pictures of the buildings, and documented my observations. I was able to interview a representative from On Lok, Dr. Mao, to gain more knowledge about the methods that she and On Lok use to provide culturally competent eldercare for their patients. However, I was not able to interview a representative from Aegis Gardens. In future studies exploring culturally competent eldercare for Asian Americans and implementation of culturally competent care methods for aging Asian Americans in settings with limited resources, it would be beneficial to shadow healthcare professionals within these environments as well as sites such as family/internal medicine clinics and traditional nursing homes/assisted living families in smaller cities in the United States that care for a small Asian American population (<5%). Through observations and interviews of patients and healthcare professionals within these sites, acknowledgements of culture during care as well as the challenges presented to provide culturally competent care can be identified from the lenses of both the patients and the healthcare professionals. Additionally, interviews with patients and residents would aid in identifying methods that patients and residents feel best acknowledges their cultural and linguistic needs. The findings from these methods could ultimately be used to contribute to the strategies and practices that can be implemented within traditional long-term and clinical care to deliver culturally competent eldercare for Asian Americans, especially within care settings with limited resources.

It is important to acknowledge the diverse histories and contexts of the subgroups within the Asian American community and how those differences create their own set of unique

challenges and factors within subgroups. In an effort for my research to reflect the unique differences within Asian American subgroups, the literature that my research draws from is varied in the Asian American ethnic groups that it represents. While some sources are broadly focused on Asian Americans as a whole, others are specifically focused on ethnic groups such as Chinese Americans or Korean Americans. Within my interviews, I focused broadly on Asian Americans in both settings. The findings of my research will broadly have implications for Asian Americans as a whole.

Section 1: Growing Aging Asian American Population

Throughout my thesis, aging or older refers to individuals who are 65 years and older.² The Asian American cohort refers to the racial group in the United States consisting of 22 million people tracing their roots to over 52 countries in East Asia, Southeast Asia, or the Indian subcontinent (Asian American Health Initiative). Currently, Asian Americans make up 7% of the United States population with the Asian population nearly doubling between 2000 and 2019. The largest Asian origin group is Chinese Americans making up 24% of the Asian American population followed by Indian Americans (21%), Filipino Americans (19%), Vietnamese Americans (10%), Korean Americans (9%), and Japanese Americans (7%). Approximately 57% of Asian Americans were born in another country.

The immigration history associated with Asians within the United States is diverse. Immigration of Asians to the United States took place during the mid 1800's to the early 1900's due to the sugar and pineapple plantation era in Hawaii, the California Gold Rush, and the Transcontinental Railroad periods as well as during World War II, the Korean War, and the Vietnam War. The largest wave of Asian immigration occurred after the Immigration and Naturalization Act of 1965 was passed. Those included in this substantial wave of immigration are first- and second-generation Asian Americans who are now approaching ages of eldercare recipients and caregivers respectively, demonstrating the relevance of exploring culturally competent care in aging Asian Americans (Choy 5). This ongoing immigration from Asia contributes to the increase in the "minority majority" population (Frey). According to the healthy immigrant effect, immigrants are found to be in better health than their American-born

 $^{^{2}}$ 65 and older serves as "the federal marker for old age" as it is when Medicare and Social Security eligibility begins (Mann).

counterparts but their health advantages consistently decrease the longer they have been in the United States. Immigrants also have less adequate access to formal medical care (Frisbie et al. 372).

Asian Americans are the fastest growing minority population in the United States, and the Asian American population is projected to surpass 46 million by 2060 (Budiman and Ruiz). By 2040, whites are expected to account for less than 50% of the population (Coolen). Despite the Asian American population being the fastest growing racial group in the United States, these communities are understudied and thus, underserved (Montenegro 5). Additionally, Asian Americans are often lumped into one category in terms of health data and research and as a result, meaningful differences amongst subgroups in the findings may be masked (Pak). The aging Asian American population reflects the projected growth in Asian Americans in the United States as a whole. According to the Administration on Aging, part of the Administration for Community Living, an operating division of the U.S. Department of Health and Human Services; the Asian American population age 65 and older was 2.49 million in 2017, and it is projected to grow to 7.9 million by 2060 (2). Racial and ethnic minority populations ages 65 and older are projected to increase by 115% between 2019 and 2040 compared to the white population ages 65 and older which is projected to increase by 29% between 2019 and 2040. This 115% projected increase amongst racial and ethnic minority populations age 65 and older can further be broken down: Hispanic (161%), African American (not Hispanic) (80%), American Indian and Alaska Native (not Hispanic) (67%), and Asian American (not Hispanic) (102%). Accounting for the majority of the increase among racial and ethnic minority populations age 65 and older, aging

Asian Americans accounts for the largest projected population increase amongst any racial and ethnic group (Administration on Aging 5).

The increasing proportion of Asian American caregivers reflects the rapidly growing rate of the Asian American elderly population. According to the AARP, 42% of Asian Americans and Pacific Islanders help to care for elders compared to 22% of the general population. Montenegro found that the vast majority of Asian Americans feel as though caring for their parents is expected of them, demonstrating the value of filial piety within Asian American culture. As a result, there is a high incidence of aging Asian Americans living in multigenerational households. However, the tradition for Asian American children to care for their parents is slowly eroding as families are geographically dispersed, both spouses within families work, and the rates of fertility continue to decrease (6). According to the United States' most recent census, the United States per capita birth rate has declined for six consecutive years to 1.6 due to urbanization. In order for a country to naturally replace its population, its per capita birth rate needs to be at least 2.1. This population decline will create forceful effects on our society and the future of eldercare. "In the 1960s, there were six people of working age for every retired person. Today, the ratio is three-to-one. By 2035, it will be two-to-one." (Bricker). This dramatically impacts the future of caregiving as the care needs of the aging population grows and the number of available caregivers shrinks (Scommegna 8). As a result, retirement communities for Asian Americans, efforts to be more culturally sensitive in nursing homes and at-home care, and programs and resources for caregivers caring for Asian Americans are rising (Vega). As the United States shifts into an even more diverse multicultural society, these aforementioned factors

demonstrate the importance of establishing high quality care that is culturally competent and effective.

Section 2: Importance of Culturally Competent Care

Patients' culture may have a strong influence on their responses to illness and healthcare. Culturally competent care is based on the development of trust between the patient and healthcare provider as the provider delivers care that fits within the unique cultural context of the patient. Within a patient-provider relationship in the context of aging, eldercare, long-term care, and eventually end-of-life care, the provider must be attentive to not only the patient's physical health but also to the psychosocial, existential, spiritual, and religious aspects of their needs. A person's aging years and especially those as they approach the end-of-life are often difficult to discuss and especially with one's healthcare provider. This challenge can be furthered when the cultural norms of a patient differs from those of their healthcare provider. In order to achieve quality end-of-life care, enhanced cultural competency is an identified need so that healthcare providers have a clear understanding of the "unique and specific influences culture has on a patient's behavior, attitudes, preferences, and decisions around end-of-life care", says Coolen. Because American values can conflict with the values of ethnic and racial groups such as Asian Americans, neglect in addressing the nuanced ways culture may impact a patient's healthcare can lead to "health disparities resulting in fragmented care, inadequate or inappropriate symptom management, miscommunication with the patient and family, and a difficult and poor death for the patient" as supported by numerous studies (Coolen).

Among aging Asian Americans, there are various cultural factors to consider in eldercare and eventually end-of-life care. Specifically, one must consider patient's and family's perspectives on death and dying, advance directives, health and suffering, hospice and palliative care, acceptance of Western healthcare practices and use of alternative traditional practices,

spiritual and religious beliefs and practices, role of the family and decision-making preferences, and need for interpreting services (Coolen; Searight and Gafford 515). In her guide to Cultural Relevance for Asian Americans in End-of-Life Care, Coolen breaks down cultural competency into six key elements: desire (motivation to commit to becoming culturally competent by seeing individuals as unique and worthy of quality care), awareness (sensitivity, respectfulness, and attention to the patient's cultural beliefs and practices), knowledge (the process of developing understanding of cultural groups' values, beliefs, lifestyle practices, and perspectives), skill (cultural assessment by obtaining a patient's individual relationship to culture), collaboration (partnership between the provider, patient, and family), and encounter (seeking cultural experience through engagement and immersion of the culture).

It is important to acknowledge that for Asian Americans and especially immigrant Asian Americans, assimilation is on a spectrum that differs individually based on various factors. Asian Americans may experience identity conflict defined by Nugraheni and Hastings as "when an individual perceives certain aspects or attributes of him-herself which s/he rejects simultaneously" that emerges as a result of acculturation. Asian American immigrants must balance attachment and maintenance to their culture and traditions while also facing the pressure to assimilate to American norms (93). Additionally, there is stark heterogeneity within Asian American subgroups as their cultures, languages, and histories vary due to Asian American groups originating from approximately 52 diverse Asian countries. While generalizations about groups of people can be meaningful, it is important to acknowledge that individual variations and exceptions exist due to variability arising from many factors including biculturalism³ (Choy 12).

³ Biculturalism is the extent to which a person adopts values of both the ethnic culture and the mainstream American culture (Choy, 12).

Coolen points out that it is imperative to treat patients as individuals as patients do not always maintain beliefs associated with their ethnicity due to the great diversity within a community.

Section 3: Asian American Cultural Factors to Consider in Eldercare

A. Filial Piety and Familial Decision Making

East and Southeast Asian countries are strongly influenced by Confucian principles that spread during China's Han dynasty and remain influential within the Asian American population in the United States today. Filial piety is the Confucian notion grounded in moral principles that children must care for their parents in old age, focusing on the parent-child relationship through respect for one's parents, not bringing dishonor to one's parents, and caring for one's aging parents. The relationship between a parent and a child may have the implications in which rearing a child is perceived as an investment with an expectation of later repayment as parents have given their children life and have raised them which are viewed as "monumental contributions practically insurmountable to repay" (Choy 17). The traditional concept of filial piety advocates for care, support, honor, and respect as adult children caregivers should feel a sense of happiness and personal fulfillment. Genuine respect and care must be accompanied with caregiving in order for it to be sufficient (Choy 18). Filial piety is a virtue that takes on a different meaning and fulfillment based on an individual and their family. Based on differing cultural belief systems and levels of assimilation between a parent and child, an Asian American child's expectations may differ from their parents' in terms of caregiving and the roles of adult children in regards to their parents' healthcare (Choy 2).

Dr. Alice Mao, a geriatrician practicing at On Lok in San Jose, California, states that some of Asian American patients request that their children make their healthcare decisions or that they want to do what she, as their provider, recommends. She elaborates that many patients

feel as if the burden of decision making is alleviated when another trusted individual shares, does the decision making, or initiates the decision making process. With patients who prefer family-based or physician-based decision making, she still uses a scale from 1 (indicating that they want no medical intervention) and 10 (indication that they want every intervention possible) to understand and document their general beliefs in regards to end-of-life situations while still respecting and honoring their wishes regarding involvement of family members.

The collectivist values that Asian Americans possess may conflict with American individualistic values. American values emphasize autonomy in healthcare which can challenge a provider caring for an Asian American patient with values that differ or conflict such as informed consent and truth-telling (Coolen). Many Asian and Native American cultures value beneficence and nonmaleficence over autonomy as autonomy can be seen as isolating rather than empowering (Searight and Gafford 516). Due to principles such as filial piety, collectivist culture, and familial decision making, it is not uncommon for healthcare professions outside of the United States to withhold diagnoses from patients if that aligns with their wishes. This is a clear example of a clash between the Western value of autonomy with preferences for family based, physician based, or shared physician and family based decision making among other cultures (Searight and Gafford 515). Searight and Gafford stress that by respecting a patient's wishes to not receive diagnostic information or to fulfill family or physician based decision making preferences, the healthcare team is honoring the patient's voluntary choice and thus honoring their autonomy (519).

Additionally, Asian American immigrants may be accustomed to their physician making their healthcare decisions in their home country as physicians are seen as highly respected authority figures. As a result, Asian American patients and families may have the expectation that it is the physician's role to make their healthcare decisions (Searight and Gafford 519). On the other hand, in her healthcare quality survey of 3,205 white patients and 521 Asian American patients, Ngo-Metzger et al. found that only 59.4% of Asian Americans felt as if their doctors involved them in care decisions as much as they wanted compared to 79.6% of their white counterparts. Less than half (47.1%) of the Asian American participants felt that their doctors listened to everything they had to say. They state that this finding may be explained by cultural differences in communication style as Asians often nod and smile to show respect to their provider. This provider may misunderstand these gestures as agreement. As a result, Ngo-Metzger et al. propose that the provider specifically asks the patient if there are any problems with the treatment plan proposed to ensure that the patient and provider are on the same page (116-117). Because of the complexity that is associated with an individual's values and the factors that contribute to their values, it is imperative to understand a patient's individualized preferences for receiving information, desires about involvement in clinical decisions, and the desired role of their family members so that healthcare decisions can be made accordingly (McCabe et al. 94). Searight and Gafford offer the following questions as examples: "Some people want to know everything about their medical condition, and others do not. What is your preference?" and "Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make them for you?" (519).

B. Alternative Medicine

Coolen states that Western medicine is generally accepted by ethnically diverse patients in the care of terminal illness but that it varies depending on many factors. Some Asian American patients may want to seek alternative practices through herbs, acupuncture, moxibustion, spiritual healers, cupping, coining, and palm reading. In M. Lee et al.'s exploration of barriers to healthcare access in 13 Asian American communities in Maryland, over 75% of the 174 participants reported that they used some form of complementary and alternative medicine within the past year. Physicians should explicitly ask Asian American patients about supplement and herbal use as patients often do not think to mention this when asked about their medication use (Nguyen 491). Due to the effectiveness or perceived effectiveness, Coolen suggests that alternative medicinal practices be utilized alongside Western medicine. Dr. Mao asks her patients to bring in any nonprescription medication that they take so that she can ensure that the active ingredients do not interfere with their other medication. If traditional Chinese medicine or other alternative medicinal practices such as acupuncture are used by her patients, Dr. Mao utilizes Western medicine alongside them as long as they are not dangerous or interacting with other medications as they can be effective. Finally, it is important to address misconceptions of Western medicine so that the patient is able to make an informed decision as some Asian Americans may possess the belief that Western medicine is more potent and has greater side effects than alternative medicine (M. Lee et al. 3).

C. Influence of Faith and Spirituality

Faith and spirituality can play a substantial role in a person's life and thus affect their healthcare perception and eventually their end-of-life responses and beliefs. Buddhist beliefs that are prevalent in Southeast Asian Americans include the cycle of life, karma, reincarnation, and death as a part of life. Families may request that a monk prays at the bedside of a family member to aid them in their journey to the next life. Aggressive treatment may be viewed as disturbing the natural cycle of life and in turn resulting in a bad death. Samoan, Vietnamese, and Indian culture holds the belief that dying away from the home can lead to disturbances of spirits. Similarly, dying at home is encouraged in Korean culture. As a result, palliative efforts may align with these beliefs and values. On the other hand, there is a belief within Chinese culture that dying at home causes ghosts to linger within the home. For Filipino Catholics, the family may request a priest to give the sacrament of the anointing of the sick to bring strength to the person. A priest may also be requested so the person can ask for forgiveness for their sins to gain peace as they go through the dying process. Additionally, evening prayers with family and friends may be held by the family to support the person. The Hmong, an animist religion, may hold spiritual ceremonies by a shaman as they believe the cause of illness is due to an evil spirit or a curse.⁴ Also, due to the Hmong belief of reincarnation, the shaman can also help the person transition to their next life. Among Somali Muslims, prayers are important at the end of life. Consequently, an effort may be made for the patient's last heard words to be from the Quran as it is believed that these prayers allow their soul to enter paradise after death. Moreover, the family may request that the patient's bed is facing toward Mecca as Muslims pray towards Mecca (Coolen). Through the

⁴ Animism is the belief in the spirit world and in the interconnectedness of all living things (PBS).

diversity of religious backgrounds associated with Asian American subgroups, the importance that faith and spirituality can have on healthcare and specifically, end-of-life care is evident. The understanding of a patient and their families' religious and spiritual beliefs and how they relate to their care and end-of-life wishes is essential in order for their provider and care team to best acknowledge these wishes as each patient possesses individual beliefs, values, and wishes. Searight and Gafford suggest using a question such as: "Is there anything that would be helpful for me to know about how your family/community/religious faith views serious illness and treatment?" (519).

Furthermore, the way an individual expresses pain can present difficulties in a healthcare provider's assessment of the patient's pain. Buddhist and Confucian beliefs of fatalism propose that pain is to be endured as it can lead to spiritual growth. Patients with these beliefs may not express their pain to their care team presenting barriers to effective pain management. It is important for providers to assess and understand a patient's views regarding pain management such as preference for traditional healing practices and fear of addiction of being overly sedated (Coolen).

D. Advance Directives

Advance directives are legal documents in which individuals communicate their end-of-life medical care preferences to family and healthcare professionals in advance in the event that they become unable to make their own decisions (Sun et al. 2). Advance directives not only reduce decision-making burdens, but they also improve the quality of end-of-life care and reduce healthcare expenditures (Jang et al., "Knowing-Doing Gap" 874). Ethnic minorities and

specifically Asian Americans are less likely to complete advance directives when compared to whites (Salmond and Estrella 117). In her study using data from 2609 participants in the 2015 Asian American Quality of Life survey, advance directive completion rates of Asian Americans was 12%, much lower than that of the general population of the United States of 26-36% (874). These lower rates can be attributed to lack of knowledge and understanding about advance directives, unclear instructions, preference for physicians to make/initiate healthcare decisions, limited access to advance care planning information and assistance, and death and dying as taboo (Sun et al. 2). Due to the high regard of healthcare providers, some aging Asian American patients may prefer that their provider initiates the discussion on end-of-life decisions.

Coolen suggests for providers to communicate to patients and their family members that an advance directive does not mean that the patient and their treatment will be abandoned. Dr. Mao suggests using advance directives in the patients' native language with pictures so that they better understand the questions and their implications. As a result, the patient can thus more adequately make decisions regarding their end-of-life care. She opens up the discussion with her patients by asking the patient if they or someone they love has ever been in the hospital before and asks about their experience if applicable. Then she determines their general stance on end-of-life care: "If you were to ever to get very sick and have to go to the hospital and the doctors there don't know you, where do you stand on a scale of 1-10 with 1 being let me die without medical intervention and 10 being try every medical intervention possible" (Mao). She ensures each patient that their advance directive can always be revisited and amended if their end-of-life choices change. Additionally, advance directives can be promoted in community settings such as religious and community centers. In a study of a church-based, culturally tailored

program to promote completion of advance directives among Asian Americans, there were significant increases in the participants' knowledge, intentions, and supportive belief and attitudes related to advance directives. As a result 71.8% of participants completed advance directives and 25% had conversations about advance care planning with a designated proxy (Sun et al. 1).⁵

E. Mental Health

In their study, Ngo-Metzger et al. found that Asian Americans were less likely (11.78%) than whites (21.32%) to report that their doctors talked to them about mental health issues. She states that this may be explained by the characterization of Asian Americans as the "model minority" with marginal health problems. However, Southeast Asians have high rates of depression and post-traumatic stress syndrome (115). The unique challenges facing Asian Americans include pressure to conform to individualist societal norms that conflict with traditionalist family expectations, assimilation to the culture of a new country, trauma faced within war or immigration, and anti-Asian sentiment (Kramer 230). Kramer states the importance of identifying an Asian American patient's cultural views on mental health and to reassure patients that they may talk about their problems without judgment due to the common perception of healthcare providers as authority.

Traditional beliefs about mental health and their causation shape the expression and recognition that Asian American patients have. For example, there is a Chinese belief that mental illness is caused by lack of harmony, a Japanese belief that mental illness is caused by evil

⁵ There were 174 participants from 4 churches (Sun et al. 1).

spirits, or the Buddhist belief that struggles in one's current life are caused by transgressions committed in a past life. Because of the Confucian, collectivist tradition that discourages displays of emotions to maintain social and familial harmony or to avoid appearing weak, mental health is stigmatized in many Asian cultures as it can reflect poorly on an individual or their family. Mental illness in Asian culture can be seen as taking away from a person's ability to care for themselves and others, and thus, being the ultimate form of shame. It is commonly attributed to one's circumstances instead of their psyche (Kramer 228). In addition, some Asian languages don't have a word for depression (Bilkhu). As a result, many Asian American patients express psychological distress somatically as expression through Western mental health symptoms such as hopelessness, loss of interest in life, depressed mood, and suicidality may be taboo. Instead, Asian American patients may state that they have a racing heartbeat, insomnia, headaches, fatigue, abdominal pain, or a change in appetite (Kramer 228). This lack of translatability of mental illness from the dominant Western culture to Asian cultures proposes a barrier to the effective recognition and treatment of mental illnesses. She recommends that providers identify sources of support within a patient's interpersonal relationships as it aligns with collectivist values of leaning on community and therefore, increases treatment adherence and reduces barriers.

The awareness of somatic presentations in Asian American patients is important as providers are less likely to experience miscommunication with their patients. There are instances in which Asian American patients with language barriers point to their heart to indicate worry for their health or to their head to express anxiety and stress (Coolen). In the instance that providers are unsure of what their patients are communicating, utilizing interpreting services and health

explanatory belief model questions such as "What do you think caused your problem?" and "What kinds of medicines, home remedies, or other treatments have you tried for this sickness?" are essential to clarify a patient's experiences, thoughts, and needs (Kramer 231).⁶

F. Eastern Diet

Nutrition is an integral part of an individual's health, and Eastern and Western nutritional concepts vary in many ways (Wongvibulsin et al. 1). In Wongvibulsin's analysis of Eastern and Western nutrition, she compares traditional Chinese nutrition and United States nutrition. The primary goal of Eastern nutrition views food as a way to achieve balance and harmony within the body (4). In traditional Chinese nutrition, yin-yang (hot and cold) and the five phases (sweet, acrid, sour, bitter, and salty) describe not only the food but also the person consuming the food. Because each individual has a unique lifestyle and environment, it is believed that their diet must aid in this balancing act to achieve equilibrium. For example, an individual with a hot constitution is recommended to follow a diet with a cooling nature (5). In Eastern nutrition, inflammation, the body's mechanism to fight against infection, is thought to be caused by internal heat derived from the dominance of yang (7). This heat comes from dysregulation of internal organs, psychological stress, and heat-producing foods (known as pro-inflammatory foods in Western nutrition) (8). These principles and beliefs contrast with the Western focus on regulating and ensuring the caloric intake of essential nutrients. The Western approach views diet through individual parts making up a whole while the Eastern approach views diet more holistically. However, both views advise minimizing/eliminating foods that are highly processed, fried, and high in sugar and saturated or trans fats and increasing consumption of whole grains,

⁶ See Kramer 231 for the full list of explanatory belief model questions.

lean protein, fruits, vegetables, and nuts (8). Additional considerations regarding diet include awareness of the typical rice-based diet in regards to diabetes counseling, low levels of calcium intake (especially for Asian women), and high rates of lactose intolerance (Nguyen 492; Asian American Health Initiative; Coolen).⁷

G. Preventative Screening and Risk Factors

Asian Americans, compared to other racial and ethnic groups, are less likely to report that they have a primary care provider (Pak). Because Asian American and especially immigrant Asian Americans typically seek medical care only when they feel symptoms, healthcare providers should emphasize screening and prevention during sick visits in addition to well visits as many Asian Americans do not schedule health maintenance visits (Nguyen 492). In M. Lee et al.'s focus group, they found that many Asian Americans have misconceptions in regards to use of the healthcare system. In many Asian countries, there is a phenomenon in which healthcare is only used when someone becomes very ill. As a result, preventative care including screening and blood pressure, cholesterol, and glucose level monitoring is not typical and as a result, Asian Americans do not understand the importance of and thus seek healthcare services when they are not very ill (10). Physicians should not assume the same health literacy for immigrant patients as American-born patients. Despite the common perception that all Asian Americans are well-educated, many Asian American immigrants have low educational attainment and poor medical knowledge (Nguyen 491). Additionally, being older, poor, or uninsured also constitute barriers to healthcare access (Yoo et al. 75). In regards to treating patients at risk for chronic

⁷ The average calcium, an essential nutrient for bone health, intake for Asian women has been observed to be half that of Western population groups (Asian American Health Initiative).

conditions, greater effort must be taken to educate patients and families about the long-term implications and the potential for patients to change outcomes (Nguyen 491). As a result, it is important to stress the importance of annual doctor visits and preventative care (Pak). Because cancer is the leading cause of death amongst Asian Americans, and advancing age is the most critical risk factor in the development of all cancers, the importance of screening must be emphasized to patients (Yoo et al. 75). By proactively addressing the health literacy, linguistic needs, and cultural nuances relevant to Asian American patients, healthcare providers can take advantage of opportunities to care for a population that has often been underserved (Nguyen 492).

In his comprehensive list of preventive services to consider for Asian American patients, Giang T. Nguyen lists anemia screening, cancer screening, diabetes mellitus screening, glaucoma screening, hepatitis B & C screening, HIV screening, intestinal parasite screening for recent immigrants and refugees, mental health assessment as previously discussed, osteoporosis screening, tobacco counseling, and tuberculosis screening (492).⁸ The prevalence of these conditions may be attributed to infrequent medical visits and thus lack of screening and preventative services, language and cultural barriers, and lack of health insurance (Pak). Other considerations to take include nasopharyngeal cancer, sensitivity to beta blockers, and ankylosing spondylitis (Coolen, Mao). With the awareness of the prevalence of certain health

⁸ Thalassemia is common in Asian populations. Asians are the only group in the United States for whom cancer is the leading cause of death, yet cancer screening is low. Breast, colorectal, and cervical cancer screening should be promoted. There is an increased risk of glaucoma for older Asians. Hepatitis B can lead to cirrhosis and liver cancer. There is high hepatitis B endemicity in Asia. American-born Asians may still be at risk through vertical transmission from an infected mother. Older Asian women are at risk for osteoporosis, partly due to the typical diet being low in calcium. Asian immigrant men are more likely to smoke than other Asian subgroups. Asians are the most at-risk racial group for tuberculosis in the United States (Nguyen, 492).

conditions within the Asian American population, healthcare professionals may be more likely to encourage screening, advocate for prevention, and identify signs early on.

Section 4: Existing Models & Methods of Culturally Competent Eldercare for Asian Americans

A. Ethnospecific Long-Term Care Facilities

Due to diminishing filial piety, increasing individualism, eroding expectations of caregiving from adult children, insufficient housing, being geographically far from adult children and extended family, and adult children having to work, more Asian American care recipients are turning to long-term care facilities (Choy 51; AARP 6). From 1999 to 2008, the number of white residents in nursing homes has decreased by 10%, while the number of Asian residents has increased by 54%. This trend indicates the relevancy in evaluating long-term care use by Asian Americans (Jang et al., "Willingness" 668). In Jang et al.'s study using data from 2,553 participants ages 18-98 residing in Austin, Texas in the 2015 Asian American Quality of Life Survey, they found that 38% of participants demonstrated willingness to use a nursing home. Those with advanced age, female gender, Korean ethnicity (compared with Chinese), better education, presence of a chronic medical condition, longer years of residence in the U.S., and lower levels of family solidarity expressed greater willingness ("Willingness" 668). In a similar study in New York City, New York, 13.2% of older Asian American demonstrated willingness to use a nursing home. These differences between these findings can be attributed to differences in age ranges of participants, years of data collection, and location ("Willingness" 672). Jang et al. state that further attention should be paid to geographic variations evaluating the willingness to use a nursing home of older Asian Americans as the availability of and access to culturally competent long-term care options may influence willingness to use a nursing home

("Willingness" 672). Oftentimes, elders use nursing homes when options for care are exhausted (E. Lee 32).

In traditional nursing homes or assisted living facilities, the aging Asian American population may have challenges such as the inability to effectively communicate with the staff, care team, or other residents; unfamiliarity with the food available; and disinterest with the activities due to their cultural and linguistic differences. These challenges can lead to feelings of isolation and withdrawal which can in turn result in its own physical and psychological dangers as culture is a vital aspect of identity with a huge impact on an individual's well-being (Span 2). In their study of the experiences of Korean elderly people living in a traditional nursing home in Philadelphia, Pennsylvania, Suh and Park found that Korean residents felt as if they were "thrown in a different world" in which their culture wasn't considered and language barriers caused challenges in care. Moreover, the Korean residents disliked American food and ate small amounts sometimes resulting in failure to obtain proper nutrition. Finally, healthcare professionals assessed the residents as having poorer cognitive and behavioral functions than they did as a result of their unfamiliarity with their culture and inability to communicate with them (Suh and Park 333-336).

Through the clustering model and ethnospecific long-term care facilities, residents are able to engage with vital parts of their culture and identity in aspects including food, activities, and community. The clustering model groups members belonging to the same ethnic group together in a facility so that it is easier to develop services curated to their culture. In clustered homes, patients adjust better due to the company of residents from similar backgrounds that they can often communicate with in their native language (E. Lee 38). Additionally, the clustering

model allows residents to interact with other residents' visitors which is especially beneficial for residents who do not have visitors often. Critics of the clustering model remark that it encourages segregation, residents from the same ethnic background are not necessarily compatible, and it can be costly as it is difficult to hold empty beds (E. Lee 39).

Ethnospecific nursing homes and ethnospecific programs within traditional nursing homes provide culturally competent care and acknowledge residents' culture in the many elements of care nursing homes provide. As a result, residents benefit from having a sense of cultural familiarity (Kwong). There is limited literature on Asian American ethnospecific long-term care facilities and ethnospecific long-term care facilities in general. Few studies compare ethnospecific nursing homes and traditional nursing homes. Moreover, there is no composite information on the availability of ethnospecific long-term care facilities to better access and understand the landscape of these models of care. While ethnospecific nursing homes, assisted living facilities, and retirement communities can be found through using search engines by searching for facilities in a specific location, there is no formal directory available even when searching for statewide directories.

In Eun-Hee Lee's case studies of three Korean nursing homes on the East Coast of the United States, he describes the experiences of residents at Lake View (ethnospecific nursing home), Beautiful Tree (nursing home with special programs for Korean Americans), and Blue Sky (nursing home with special programs for Korean Americans) with 136, 100, and 32 Korean American residents respectively⁹. Each facility accepted Medicaid, Medicare, private insurance, and private pay. Additionally, all three facilities had Korean staff members who spoke Korean,

⁹ The names of the facilities in his dissertation have been changed to protect the anonymity of the participants (E. Lee, 51).

ethnics food, TV, radio channels, church services conducted by Korean pastors, activity programs such as yut, an outdoor Korean barbecue, outings to a Koreatown, karaoke, Korean movies, and teatimes (75). After Korean volunteers observed 3-4 Korean traditional nursing home residents store rice in a refrigerator and put it into hot water to make it soft before adding kimchi juice for flavor, they brought it to the attention of the long-term care manager. The facility began serving Korean food to 4-5 residents and they were very pleased. As they recognized the need for culturally competent care in nursing homes, Lake View was eventually created for Korean residents (119). At Beautiful Tree, the facility provides transportation to Koreatown 2-3 times a week where residents enjoy eating at Korean residents (126).

In 2001, Aegis Living, a leader in assisted living and memory care, announced the opening of the first Aegis Gardens location in Fremont, California. Aegis Gardens is an assisted living community with 64 units that focuses on Asian culture and honors their residents' history through their activities, architecture, family events, cuisine, and care. Each day, their chef prepares traditional Mandarin and Cantonese cuisine. Activities such as Mahjong, calligraphy, painting, cribbage, tai chi, and origami are available. Aegis Gardens maintains nearly 100% occupancy (Span 1). Festivities include traditional lion dancers, jugglers, and gymnasts. The apartment numbers within Aegis Gardens skip any number containing a 4 as in Chinese culture, it is considered unlucky. Aegis Gardens has been built based on the advice and guidance of a feng shui practitioner.

B. Ethnospecific Clinics, Culturally Competent Providers, & On Lok

Because patients are more satisfied with their care when the care is culturally competent, patients who perceive their healthcare team as culturally competent tend to be more open with and trusting of members of the team. Additionally, patients are more likely to follow the medical advice of their provider when their provider is culturally competent. Furthermore, patients who have providers who speak the same language as them correlate with high patient satisfaction (Brunett and Shingles 287-288). Finally, in an analysis of 117, 589 patient surveys from 2014 to 2017, Takeshita et al. found that patients who shared the same racial or ethnic background as their physician were more likely to rate their physicians higher than patients who see physicians of a different race or ethnicity from their own (1).

Methods to find healthcare providers who speak the patient's native language and/or who share the same culture as the patient include online provider databases, city/state-based provider directories, and ethnically and culturally diverse medical groups. Healthcare providers can be searched and filtered by specialty, location, and languages spoken on Zocdoc's website which allows patients to find and book in-person or telemedicine appointments. Examples of provider directories include the Chinese Community Health Care Association's (CCHCA) directory of physicians in the San Francisco area organized by specialty and with Chinese characters. The Physicians Medical Group of San Jose was founded in 1980 and features over 1000 physicians that collectively speak over 30 languages including Vietnamese, Chinese (Cantonese and Mandarin), Tagalog, and Korean with a website that features an online provider directory that lists the languages that each provider speaks.

Among the models and methods that acknowledge culturally competent eldercare for Asian Americans that I have researched, On Lok has been the most remarkable as it addresses the needs of aging participants while maintaining their dignity and independence. On Lok is nationally recognized as a pioneer and trailblazer for providing care for frail elderly patients (Lehning and Austin 220). On Lok was created in 1971 to address the long-term care needs of aging immigrants in San Francisco, California's Chinatown who needed services to maintain their independence at home as traditional models of care were not meeting their needs. Dr. William L. Gee, a dentist, and Marie-Louise Ansak, a social worker created On Lok to provide a community-based model of healthcare and supportive services. On Lok in Cantonese means "peaceful, happy" abode. In 1973, On Lok launched its first adult day health center where seniors could enjoy hot meals, receive healthcare services, and interact with other participants. In 1974, On Lok began being reimbursed by Medicaid for its services. In 1987, On Lok launched the Program of All-inclusive Care for the Elderly or PACE are programs within the United States that provide comprehensive health services for individuals 55 years old and older and categorized as "nursing home eligible" by their state's Medicaid program. PACE's ultimate goal is to provide older adults who want to stay within their communities with the care and services they need to continue living at home. In 1997, PACE became a permanent provider type under Medicare and a state option under Medicaid. PACE has been replicated nationwide with 272 PACE centers in 30 states caring for over 55,000 patients (On Lok). On Lok's senior day health centers provide medical, dental, podiatry, audiology, optometry, and physical therapy care along with a space for participants to interact with one another. As an On Lok provider, Dr. Mao is able to work with an 11-member interdisciplinary team including social workers, physical therapists,

caregivers, dietitians, and drivers to develop personalized care plans for patients and their families (On Lok). Additionally, On Lok provides transportation to clinics and adult day health centers, interpreting services, and caregivers¹⁰ to assist with the tasks of daily living.

C. Interpreting Services

In August of 2021, I volunteered at the Jackson Free Clinic, a student run non-profit organization in Jackson, Mississippi, offering medical, dental, psychiatric, physical therapy, and occupational therapy services to uninsured patients. Care teams consisting of 2-4 medical, pharmacy, and undergraduate students working with attending physicians each saw 3-4 patients each day, a way for students to apply their medical knowledge clinically while also addressing the needs of the uninsured patients in the Jackson metropolitan area. I was paired with a 4th year medical student, Anthony, who was enthusiastic to show me the ropes. We received the chart of our second patient that day, and I instantly noticed that she had a Vietnamese sounding last name. As we called her name, she and her nephew, holding her bag of medication, sat down in the exam room. He explained that she only spoke Vietnamese, and that this was her first time here. She usually traveled 3 hours to see her Vietnamese-speaking primary care provider in Baton Rouge, Louisiana, but he was no longer practicing. I could see her apprehension as this was her first time at a new clinic and the staff didn't speak her native language. As Anthony asked her questions about her medical history, her nephew translated. At times, it was clear that he struggled to find the right words to relay back to us. As we left the exam room to present to the attending, I asked Anthony if there were interpreting services we could utilize in situations like

¹⁰ On Lok interpreting services, caregiving, and caregiving support will be discussed in subsequent sections of this chapter.

these, and he told me they didn't have Vietnamese interpreting services available. I worried about the relevant information we were losing without an interpreter, and I thought of the times my parents had to translate for my relatives with limited English proficiency. It wasn't surprising to me that our patient would travel so far just to receive care from a primary care provider who spoke the same language as them.

Interpreting services can be delivered in a variety of ways: by phone, over video conference, through telehealth platforms, or in person (GLOBO). While there are costs¹¹ to providing these services, utilizing interpretation services can save money by reducing medical errors and preventing medical costs such as hospital readmissions (Karliner et al. 1)

According to the Pew Research Center, 57% of foreign-born Asian Americans were proficient in English in 2019 (Budiman and Ruiz). In Tonkin's article on the importance of accessible medical interpreters, she explains that Executive order 13166, "Improving Access to Services for Persons with Limited English Proficiency" was signed and enacted in 2000 in accordance with Title VI of the Civil Rights Act, which prohibits discrimination on the basis of national origin. Consequently, federal agencies including healthcare agencies must provide services consistent with this Executive order for limited English proficiency persons including interpreting services. Despite this order, data shows that medical interpreters are underutilized in the healthcare setting (13). Limitations result in weak enforcement of interpreting services (Ostrovsky 51). In 2016, a survey by the American Hospital Association suggested that only 56% of 4,586 hospitals offered some sort of linguistic and translation services. Mara Youdelman, managing attorney at the National Health Law Program in Washington, D.C. says "It shouldn't

¹¹ Medicare does not reimburse providers for interpreting services (Levinson 7).

be an add-on. It should be a required part of providing high-quality healthcare." (Eldred). In order for a patient to make informed decisions regarding their health, adhere to their treatment plan, and understand their health condition, they need the ability to freely communicate with their provider and other members of their care team.

At On Lok, they have staff that speak various languages concordant with the languages their patients speak allowing in person interpreting which is helpful for patients who have hearing loss or for patients with dementia. For the most part, a telephonic interpreter service called LanguageLine Solutions is used in clinic visits where the provider is connected with an operator that matches them with an interpreter who speaks the patient's preferred language (Mao). Furthermore, when On Lok sends patients who don't speak English to specialty visits that don't have interpretation services. On Lok sends a caregiver with the patient who can act as an interpreter for them. Dr. Mao says some clinics and hospitals use video interpretation services which are helpful for patients who have more cognitive impairment as well as deaf patients. From a geriatric lens, while using interpreting services, Dr. Mao recommends making sure her patients who are hearing impaired have their hearing aids and are sitting close to the phone with the speaker turned to the maximum volume. She also suggests investing in a Pocket Talker, an amplification system with a headset and microphone intended for improved communication in difficult listening situations amplifying sounds close to the listener while reducing background noise. She speaks into the microphone or puts it next to the telephonic interpreter allowing the patient to hear better and more clearly.

Dr. Mao recommends that family members are not used as interpreters as they are not professional interpreters and often edit what patients are saying based on what they already know. It is important for the provider to know word for word what the patient is saying and for the patient to know word for word what the provider is saying without editorializing either way. In her article exploring patient use of family members as non-professional interpreters, Rimmer advises that the "gold standard" is to use a professional interpreter for patients who don't share the provider's language as there are many risks associated with using family members as interpreters. While interpreters are neutral and passive due to their training and experience, family members may find it difficult to be neutral and passive. Also, they may find it hard to share difficult news, may give the provider their own version of events, or may distort messages to the provider or to the patient (1). The patient may be reluctant to disclose all relevant information through a family member if they don't feel comfortable sharing personal details. Research over the past 15 years has shown that language errors and misunderstandings are common when professional interpreters are not utilized (Eldred). Rimmer advises that family members should be used as interpreters with caution, and in alliance with the patients' best interests (2). Additionally, family members are important parts of the care team and they need to be able to focus on the care that their loved one is receiving so acting as an interpreter hinders their capacity to serve as a supporting family member especially in emotional conversations. Dr. Mao observed: "The family member needs to be just the family member to support their loved one and not sort of play this complex role of an interpreter and family member."

LanguageLine is commonly used in larger healthcare facilities as there are over 200 languages available 24/7. Using technology for interpreting is relatively cost-effective as

opposed to hiring several in-person interpreters for many languages. However, it is important to note the challenges to using technology in rural areas where broadband and equipment access can be limited. Using technology-based interpreting services such as LanguageLine can be time-consuming as you must wait to be connected with an interpreter after giving patient information (Ostrovsky 43-45). In an interview with National Public Radio, Dr. Alexander Green, a physician and an associate professor at Harvard Medical School, attributes the root of the underutilization of medical interpreters to "a learning environment and organizational culture that value efficiency over effective communication" (Eldred). He calls for a shift in the system to make language access easy and an expectation. Because exams with interpreters take 50% longer, Green states this problem highlights a larger problem within medicine–the shift to value-based care in which providers are paid for outcomes instead of frequency of services. This system would reward quality of care and outcomes instead of number of visits each day (Eldred).

D. Family Caregiving Support and Home Health Services

According to AARP's 2021 Home and Community Preferences survey, 77% of adults ages 50 and older have the desire to stay in their homes and communities as they age long-term support and services in their own home or in a community setting (Binette). Caregiving is unpaid care for a relative or friend in order to help take care of themselves. This may include helping with personal needs, household chores, managing a person's finances, arranging for outside services, or visiting regularly. Caregivers may support those they are caring for in their activities of daily living such as eating, bathing, toileting, dressing, transferring, walking and instrumental activities of daily living such as medication management, shopping, doing housework, driving or using public transportation, and using the phone (Mao). Caregivers of recipients ages 50+ in the

United States have increased from 14.3% in 2015 to 16.8% in 2020, an increase of over 7 million adults serving as caregivers (AARP 4). This increase in prevalence may be attributed to one or multiple of the following factors: "aging baby boomer population requiring more care, limitations or workforce shortages in the healthcare or long-term service and supports formal care systems, increased efforts by states to facilitate home and community-based services, increasing number of Americans who are self-identifying that their daily activities are caregiving" (AARP 9). 42% of Asian Americans and Pacific Islanders (AAPIs) provide care to an older adult and 17% live in multigenerational households. Family caregiving is prevalent in Asian American families and communities due to filial ties and collectivist culture which leads to expectations for parental care based on sacrifice; a child's individualistic interests and needs are set aside for the benefit of their parents (Choy 10). 73% of Asian Americans feel a sense of responsibility to care for their aging parents compared to 49% of other Americans. Foreign-born Asian Americans are more likely to feel this way compared to American-born Asian Americans. As a result of the value of filial piety within Asian American culture, adult children may assume the moral obligation of responsibility for their aging parents, parents may resign decision making to their adult children, aging parents may reside with or near their adult children, and the family may serve as the core of social activities for parents and adult children (Montenegro 16). Asian Americans are not only more likely to take on the caregiving role, but they are also more resistant to place their elders in institutional facilities than other racial and ethnic groups (Montenegro 7). Reluctance to long-term care facilities held by Asian Americans stems from the emphasis on family caregiving, as long-term care facilities can be viewed as bringing shame on the family or disrespect to the parents (Choy 38). Older Japanese Americans with lower levels of

acculturation prefer caregivers with some similar ethnic and linguistic background and of the same sex (Montenegro 25). According to Confucian values, eldercare is provided by the first-born son and his wife. Some Asian Americans possess the Buddhist belief that if the children care for their parents, both the children and the parents will reincarnate at a higher level in their next lives (Nugraheni and Hastings 90). Aside from coresidence with children, some elderly Asian Americans prefer to move closer to children, into retirement communities, or within church/community-based facilities (Choy 51; Montenegro 25).

In her AARP piece "Caregiving among Asian Americans and Pacific Islanders Age 50+", Xenia Montenegro identifies the caregiving needs of the AAPI community: care of family elders, long term care insurance, resources and tools in caring for elders, transportation and savings to access services, information on support and available services, in-language services for some Asian ethnic groups, and culturally sensitive outreach and services for caregiving (8). As stated previously, the subgroups and individuals within the Asian American population vary in the way that they value familism, religion, culture, and assimilation to American culture and thus, caregiving needs will vary (Nugraheni and Hastings 89). In a report with recommendations for family caregiving of older adults, The Committee on Family Caregiving highlights the complexities of the nature of family caregiving as it is "both a personal and private issue as well as a public and societal concern" as caregiving for elders can be a personal, spousal, or filial responsibility but the American public has also held shared responsibility for the care of older adults through programs like Social Security, Medicare, Medicaid, the Area Agencies on Aging, and others (Committee on Family Caregiving 3). Caregiving within multigenerational Asian American households presents unique challenges such as access to services and support and

cultural differences between the caregiver and the recipient (National Asian Pacific Center on Aging). The population of elderly Asian Americans who are being cared for are mostly immigrants and thus may contrast in attitudes, beliefs, and practices as their caregivers who are mostly their more assimilated children or grandchildren (Montenegro 6). Caregivers who are Asian American (51%) are more likely than Whites (36%) to report their loved one lives in their home and report feeling high levels of emotional stress (44%) more so than either African American (29%) or Hispanic (32%) caregivers. Because of the financial, work-related, and health impacts that caregiving can have on the caregiver, many caregivers find themselves in need of information, resources, benefits, or programs but these things are difficult to find, access, or afford (AARP 8). While caregivers play an integral role in the care of older adults, they are often marginalized in the delivery of healthcare (Committee on Family Caregiving 4). Nugraheni and Hastings state that United States federal caregiving policies that are designed to create neutral policies exclude racial minority groups through eligibility criteria. Moreover, Asian Americans are underrepresented in policymaking. Finally, many Asian Americans are not able to take advantage of policy benefits due to limited choices of services, language barriers, and ineligibility to meet the program requirements, such as having United States citizenship status. 14% of Asian immigrants were undocumented in 2017. As a result, these caregiving policies don't adequately accommodate Asian American caregivers' needs and Asian cultural values. Nugraheni and Hastings recommend an amendment that allows family caregivers that are residents to be eligible for the welfare benefits to aid in caregiving needs (97).

As the need for caregiving continues to rise, caregivers carry an increasing amount of strain in many aspects of their lives. What structures and methods can be implemented to support

caregivers and to equip professional caregivers with cultural competency so that caregiving can be sustainable? As supported by research, interventions designed to support caregivers can significantly improve the quality of care delivered to care recipients. These interventions show improvement in the well-being and quality of life for both the care recipients and the caregivers. Additionally, they may result in cost savings, decrease rehospitalizations, and shorten lengths of hospital stays (Committee on Family Caregiving 6). The Committee on Family Caregiving calls on Medicare, Medicaid, and the U.S. Department of Veteran Affairs to identify family caregivers and assess and support their needs, for the Centers for Medicare & Medicaid Services to develop and implement reforms that motivate providers to engage family caregivers in delivery processes, for the training of providers to recognize and engage family caregivers so that they can provide them with support and referrals to services in the community, for increased funding for programs supporting family caregivers¹², for the exploration and adoption of federal policies providing economic support for working caregivers, for expansion of data collection and research on the experience of family caregivers, and for implementation of programs by all state governments.¹³

On Lok allocates caregivers and the amount of time they spend with a patient based on the need of the patient. Dr. Mao states that she evaluates the caregiving that family members may already be providing to assess how they can be supported. Based on this need, caregivers assist

¹² Examples include the National Family Caregiver Support Program and U.S. Department of Health and Human Services programs (Committee on Family Caregiving 11).

¹³ Some states have enacted paid and sick leave laws requiring employers to allow employees a reasonable number of earned days to care for an ill family member through an insurance model relying on minimal payroll taxes paid by employees (Committee on Family Caregiving 12). Twenty-nine states have enacted the Caregiver Advise, Record, Enable (CARE) Act requiring hospitals to have patients designate a family caregiver and integrate them into the patient's care through communication and education (Committee on Family Caregiving 14).

patients with their activities of daily living and instrumental activities of daily living accordingly. She continues to assess the caregiving system that each patient and their family members are using, and adjusts them appropriately if need changes. For example, a primary family caretaker may experience burnout. At that point, a caregiver from On Lok can come once or twice a week to provide care along with the care provided by the family member. On Lok delivers meals to patients' homes so that the family members don't have to cook as often or for patients who live alone. On Lok provides transportation services to and from the day health center as well as clinic visits to On Lok and specialty visits. Finally, many patients come to the day health center where there are caregivers as well as other patients that they socialize with to combat loneliness. There are culturally competent home health services available through agency provider programs. As mentioned previously, the PACE model is operational in 30 states. In Seattle, Kin On and International Community Health Services have partnered to raise money to build a healthcare center operating with the PACE model. Kin On has personal care assistants who speak Cantonese, Mandarin, Toishanese, Vietnamese, and Tagalog, and can shop for and cook Asian meals. They also have a Caregiver Support program that includes sending assistance through caregivers and social workers, information & referral services, caregiver education, and Alzheimer's and dementia support (Kin On). In Chicago, Sahara Home Care was started by South Asian immigrants by matching home care aides who can speak Urdu, Bengali, Hindi, Tagalog, and Malayalam with older people who live at home. Funded by the Illinois Department on Aging, they now have eleven locations (Wang).

Section 5: Conclusion & Applications of Culturally Competent Care

While some of the preceding examples and models of existing culturally competent care may be feasible in cities with smaller Asian American populations and limited resources, some are not. In both cases, there are many lessons to be learned from these regarded models and methods of culturally competent care when developing potential strategies to integrate into care settings with smaller Asian American populations and limited resources. The challenges to providing culturally competent eldercare to smaller, less established, or more diversely located Asian American communities include less Asian American healthcare professionals, lack of interpreters, and lack of cultural knowledge.

A. Education for Healthcare Providers and Professionals

By becoming knowledgeable about the way Asian American culture can shape a patient's behavior, attitudes, preferences, and decisions regarding their care, healthcare professionals are better equipped to understand and thus acknowledge a patient's culture within their care. As explored in Chapter 3, Asian American cultural factors to consider in eldercare include filial piety and familial decision making, alternative medicine, influence of faith and spirituality, lower rates of advance directives compared to whites, somatic presentation of mental health, Eastern diets, and risk factors and lower rates of preventative screening. Recognizing and acknowledging these cultural influences on care allow healthcare professionals to better understand their patients. As a result, patients may display better healthcare adherence.

Cultural competence is not only the recognition of a patients' culture but also the recognition of a healthcare professional's own culture and how that can affect their own

perceptions and biases (Ngo-Metzger et al. 110). Recognizing biases as a provider or member of a healthcare team allows for the separation of one's biases from the care that they provide to patients with views, values, and beliefs that may contrast with their own or the ones taught during their training. While caring for a patient whose values may differ from members of the care team can be extremely challenging, openness to understanding their values and how their values apply to the care they wish to receive is imperative.

Dr. Mao recommends that healthcare providers and workers utilize www.ethnomed.com as a resource for accessible articles on integrating cultural information into clinical practice. The website is organized both in cultures and clinical topics so that information can easily be identified. Additionally, she states that interpreters are great resources for cultural competency. "Not only are they professional interpreters, but they are also cultural interpreters." she explains.

Additionally, education regarding culturally competent care can also be obtained through cultural competence training for staff within healthcare facilities. To learn more about the availability of culturally competent resources in Mississippi, I spoke with Dr. Nikki Johnson, the director of special projects within the Mississippi State Department of Health's Office of Preventative Health and Health Equity. The MSDH's Office of Preventative Health and Health Equity has cultural competence training available for free and as requested by agencies and individuals around the state. Currently, MSDH holds about 2 cultural competence trainings each month. The goal of this training is to reduce disparities and access to public and community services by equipping providers in health and human services with the resources to navigate circumstances in which cultural competency is necessary. Through modules, they educate participants on social determinants of health, health disparities, equity and equality, diversity and

culture, the LEARN model and its applications, stereotypes and implicit biases, and professionalism concerning cultural competency (Johnson). Cultural competence training can help healthcare facilities identify policies or practices that may act as barriers to different ethnic and racial groups. By identifying potential barriers, they can then be addressed so that the needs of patients are better addressed. Finally, diverse staff recruitment programs can support cultural competency, especially when the staff and their cultural knowledge reflects the cultural needs of the patient population they are serving. While prioritizing cultural competence can be costly, it ultimately can offer "an essential return on investment" (Tulane).

B. Individualized Care through Communication

The emphasis on the heterogeneity amongst subgroups within Asian Americans is significant as it exemplifies the need for patients to be treated as individuals. While education about the Asian American culture is meaningful, acknowledgement of the individuality of a patient who belongs to a cultural, familial, and/or religious group is even more meaningful. The factors that shape the expression and application of one's culture in their life and their healthcare are limitless. Effective communication is essential for the management of a patient's healthcare. By demonstrating interest in culture, members of a healthcare team can develop trust and rapport with patients (Searight and Gafford 521). Dr. Mao gradually talks to her patients about end-of-life choices by asking them what is important in their lives. By learning a patient's individual beliefs and values, a healthcare team is then able to align the patient's care with those values. Later, Dr. Mao asks if they or someone they love has ever been to the hospital before. She uses a scale to determine and document their general stance on end-of-life choices. She adds that these choices are flexible as a patient may change their mind over time and with new

experiences. When discussing care plans with patients and their families and especially when utilizing an interpreter, it is helpful to confirm both the patient's and the family members' understanding of the patient's condition and treatment (Searight and Gafford 519). It must be remembered that effective communication requires the healthcare team and patient to understand one another clearly. In the case that there are linguistic barriers between healthcare professionals and a patient, interpreting services should be utilized.

C. Interpreting Services

Interpreting services are essential within a healthcare team, patients, and patients' families as clear understanding between all parties is fundamental to effective communication. Without a professional interpreter, there is a lot of information that is lost or miscommunicated (Mao). Interpreters as well as linguistically diverse materials aid in a patient and their families' understanding of their healthcare condition and plan. As a result, the patients' adherence to their healthcare plan will increase (Tulane). Prior to a difficult conversation with a patient using an interpreter, Dr. Mao meets with the interpreter to discuss what she wants to communicate with the patient so that the interpreter can advise her culturally if the interpreter shares the same culture as the patient. Additionally, the interpreter is able to interpret not only Dr. Mao's words but the intern of the information she is trying to deliver.

In her thesis addressing the issue of language barriers in healthcare in Mississippi in both rural and urban counties through hospitals, clinics and community health centers, Ostrovsky, Honors student at the University of Mississippi, suggests that health policy makers and administrators seek input from community members and healthcare professionals to better understand the communities' needs, recruitment initiatives to employ educated and diverse

professions to increase healthcare access, increased training accessibility for interpreters, improving technology in facilities, and informing patients with limited English proficiency of their rights to healthcare and language access services along with outreach efforts such as mobile clinics and health fairs traveling to underserved communities with high concentrations of minority populations (53-55). In Mississippi, community interpreter training is offered by the Office of Preventative Health and Health Equity year-round through Zoom. This training interviews prospective participants to evaluate their language proficiency to ensure that it is at a level that is suitable for training. Then, over the span of 3-4 weeks, interpreters are provided with the skills and resources in professional interpreting and medical terminology to communicate professionally in any language.

D. Incorporation of Caregivers and Family Members

It is important to understand a patient's family dynamic and what roles their family members and caregivers may play or not play in their lives and healthcare. This allows providers to involve family members and caregivers accordingly. Dr. Mao states that some of her patients want their children to make decisions regarding their healthcare. Dr. Mao integrates family members into the care of their loved ones when appropriate by calling her patients' children and/or spouse following their appointments to ensure that they are informed and included in the care that their loved one is receiving. Because caregivers spend the most time with care recipients and thus are aware of the condition and needs of their care recipients, Dr. Mao also communicated with her patients' familial and/or paid caregivers as integral members of the healthcare team. Through working along with a patient's caregiver(s) and/or family member(s), she is able to provide care that is comprehensive and to be on the same page with vital

individuals in her patients' lives. In the case that a patient's healthcare decisions are made as a family, family members can be "helpful allies in ensuring mutual understanding and promotion adherence to care plans." (Nguyen 491).

E. Accessible Advance Directives

Healthcare providers should educate aging Asian American patients on advance directives and their availability, and furthermore, provide accommodations such as advance directives in a patient's native language, the use of an interpreter, and the involvement of a patient's family in completing an advance directive. Coolen adds key points to know about an advance directive such as that advance directives become a legal document once the individual signs it and it is signed in front of two required witnesses and the patient may change words, use their own words, or create their own advance directive if desired. Five Wishes is a legal advance directive document that is written in everyday language and available in Khmer, Chinese (Traditional and Simplified), Korean, Vietnamese, Hmong, Japanese, Bengali, Ilocano, Gujarati, Hindi, Tagalog, and Punjabi. These advance directives are legally valid in 44 states including Mississippi when completed, signed, and witnessed. In states where Five Wishes documents are not legally valid, they require specific additional forms or notices. In these cases, the additional forms or notices can be attached and/or they can still serve as an aid to guide conversations about end-of-life wishes. Similarly, Dr. Mao recommends using PREPARE advance directives because they are easy for patients to understand as they utilize illustrations and are available in many Asian American patients' native languages such as Chinese, Khmer, Korean, Tagalog, and Vietnamese. Additionally, she adds that it is imperative to determine a patient's medical decision maker while providing geriatric care.

F. Community Engagement

By engaging with community resources such as state health departments, cultural competency programs, Asian-owned clinics, community clinics, health screening programs, Asian American community-based organizations, Asian American faith-based organizations, and Asian American health organizations; healthcare facilities, organizations, and professionals can uncover more information on the needs of certain populations to make healthcare more accessible. Through engagement, opportunities for specific solutions for communities such as outreach, screening initiatives, or development of materials may become more evident Dr. Mao presses healthcare providers to seek out cultural competency through local organizations in the community who are well versed in a specific community such as Asian American cultural centers or local Native American tribal organizations. Because these organizations are often passionate about culture, they are likely to be willing to share resources that can aid in better understanding a culture.

Through seeking community resources, I have identified health initiatives for Asian Americans in my home state, Mississippi. The Mississippi State Department of Health's (MSDH) Health Equity team focuses on addressing the health needs of Mississippi's minority population and the limited English proficient population through programs. As aforementioned, MSDH offers cultural competency training. They became licensed in 2016 to begin offering this training to the public (MSDH). Asian Americans make up 1.1% of the population within Mississippi, representing ~32,640 individuals (United States Census Bureau). Vietnamese and Chinese speakers are within the top 5 English language learners in Mississippi (MSDH). According to MSDH, "Being limited English proficient affects a person the moment he or she

walks into a healthcare setting. Tasks such as filling out a patient intake form, billing and payment process, and following medication can be overwhelming tasks." Additionally, the MSDH Health Equity team along with partners on the Mississippi Gulf Coast, Boat People SOS and Mercy Housing and Human Development, developed a 5-year initiative ending in 2020 to hold hepatitis B screening, education, and treatment referral for the Vietnamese American community estimated to consist of 8,500 individuals of the Gulf Coast. During the peak of the COVID pandemic, they were also able to meet members of the Vietnamese community at the Buddhist temple and convention center on the Gulf Coast that served as the site for drive-through testing and vaccination. They formed a Vietnamese task force made up of community members and representatives from cultural organizations that helps them coordinate and promote these efforts while identifying the needs that the Vietnamese population on the Gulf Coast may have. Recently, MSDH has been able to secure funding to contract with some community-based organizations to plan and implement more initiatives like these. Dr. Johnson invites healthcare professionals and facilities to reach out to their state department of health for training in cultural competency and interpreting as well as suggestions and partnerships for initiatives and projects addressing needs within cultural communities (Johnson).

G. Representation in Research

Because differential access to healthcare is one of the key factors contributing to health disparities amongst Asian Americans, research, public health policy, and funding resources should include underrepresented Asian American subgroups and Asian Americans as a whole to reflect this critical need and fast-growing population (M. Lee et al. 10). Because research brings awareness to public health trends and reveals areas in which the healthcare system may fall short in the care of Asian Americans, public health policies and funding are often based on the findings of research. Because of this, research should accurately reflect the demographic of Asian Americans in the United States so that challenges can be brought to light and thus, solutions can be created through public health policies and funding initiatives within clinical care, long term care, home-based healthcare, and caregiving initiatives.

The crux of this thesis was to draw from a multidisciplinary literature review as well as interviews with key representatives in the healthcare system to make recommendations for healthcare professionals and teams, healthcare institutions, and academia within care settings with limited resources to provide culturally competent eldercare for Asian Americans. Through the aforementioned recommendations, it is clear that providing and improving culturally competent eldercare for Asian Americans from various working parts of the healthcare system from the individual level to the institutional level as different settings may be in need of distinct resources and initiatives. As the aging Asian American elderly population continues to grow in the United States, the need for developing methods for providing culturally competent eldercare within all care settings becomes increasingly relevant and pressing.

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Appendix A

For Providers

- 1. What is culturally competent care to you and why is it important?
- 2. What considerations do you take when caring for Asian American patients?

3. What are obstacles that primary care providers face when discussing aging and end-of-life with aging Asian American patients?

4. What education, if any, have you received about providing culturally competent care?

5. How do you as a provider incorporate family caregivers as integral partners in the care team?

6. What are ways in which healthcare education and intuitions can better equip providers to care for aging Asian American patients, especially those living in communities with limited resources?

For Patients

1. What are ways in which this intuition and its healthcare professionals address your cultural and linguistic needs?

2. What are the obstacles you face when receiving healthcare due to your culture?

3. What are ways in which healthcare professions and institutions can better address and serve your needs?

4. Why have you chosen a culturally competent primary care provider? Have you ever been cared for by a traditional provider? How have your experiences differed between both settings?

5. Do you have a caregiver who helps you with personal needs, chores, or finances?Do they live with you? Are they related to you?