



Chinese American Resource Guide

2022 Edition



NHPCO

Leading Person-Centered Care

NHPCO.ORG



Chinese American Resource Guide

2022 Edition

Table of Contents

I. Chinese Americans: An Overview of Key Facts, Cultural Beliefs, Communication, and Clinical Pearls	1
II. The Coalition Model – Why a Coalition Makes Sense	7
III. Outreach Strategies	9
IV. Collaborations and Partnership Perspectives	13
V. Resources for Community Engagement	18
VI. Acknowledgements	20
VII. Appendix	21
References	28

I. Chinese Americans: An Overview of Key Facts, Cultural Beliefs, Communication, and Clinical Pearls



Overview

The Asian American community is incredibly diverse. The Chinese community is the largest Asian ethnic group in the U.S. yet represents only 25% of all Asian Americans. Other groups in the Asian community include Japanese, Koreans, Vietnamese, Thai, Laotians, Hmong, and Cambodians as well as those from South Asian countries such as India, Pakistan, Bangladesh, and Sri Lanka. Given this diversity, we chose to focus on the Chinese community, as it represents the largest Asian ethnic group in the U.S.

There are some similarities between Chinese culture and the cultures of Japan, Korea, Vietnam, and Cambodia. This is mainly because over many centuries, China has had a great influence in Asia. Therefore, you may find that some cultural issues discussed in this guide are relevant to these other communities. However, we want to emphasize the importance of listening to and learning about the unique aspects of these communities with whom you are partnering and to be mindful and not to generalize or assume.

Hospice organizations are ideally suited to provide exceptional care to all people – from specialized doctors and nurses to social workers and spiritual care providers, hospices care for the whole person. To learn how your hospice can better reach and serve Chinese American communities, consider the resources and advice offered in this guide.

This section features key cultural facts and beliefs about Chinese Americans and includes specific information about:

- Demographics
- History
- Socioeconomics
- Language
- Health Care Practices
- End-of-Life Care Cultural Beliefs and Communications
- Attitudes Towards Disclosure of Bad News
- Religion

A. Demographics



The majority of Chinese Americans are either from the mainland of China or Taiwan, an island nation only 75 miles from the Chinese mainland. People from both countries share a similar racial, ethnic, and religious background. However, there are important language and cultural differences that will be discussed later in this section. In 2019, more than 5 million Chinese people were living in the U.S., an increase from 2.9 million since the 2000 census.¹ Chinese Americans made up 1.6% of the total U.S.

population in 2019, versus 1.2% in early 2000. Chinese Americans are the largest Asian ethnic group, comprising about 27% of all Asian Americans.² Despite lower birth rates, Chinese American households tend to be larger due to the common practice of multiple generations and extended family living together.

B. History



The Chinese have been immigrating to the United States since the late 1800s. In some communities, especially in California and Hawaii, many Chinese Americans immigrated generations ago. Thus, their descendants retain few cultural elements from their heritage. However, in recent decades, there has been an increase in immigration. According to a special report from the U.S. Census in 2015, 63% of Chinese Americans were foreign born.³ Therefore their traditional culture may still be very important and prevalent in their current lives. The largest Chinese populations in the United States are concentrated in the major metropolitan areas of New York City, Los Angeles, San Francisco, San Jose, Boston, Washington DC, Chicago, Seattle, Honolulu, and Houston.³

C. Socioeconomics



The Chinese American population is economically diverse; overall it does well on measures of economic well-being compared with the general U.S. population.⁴ The median income is higher than the national median income, and Chinese Americans were slightly less likely to live in poverty than the national average (14.4% vs. 15.1%) in 2015.^{3,4} The decreased poverty rate may be explained by the shifting composition of recent Chinese international migration, from the lesser skilled and lesser educated to the highly educated, wealthy, or both (>80% of emigrants).⁵ There are also more Chinese international students in the U.S. than from other countries, surpassing 350,000 in the 2016/17 academic year and accounting for one in every three international students.⁶

D. Language



Mandarin is the official language of mainland China and Taiwan. It is only one of many Chinese languages spoken around the world. Cantonese, Shanghainese and Fuzhounese, for example, are spoken by millions of people. However, all Chinese spoken languages share one of the two common written forms: traditional Chinese characters or the simplified form adopted in mainland China to increase literacy. Cantonese favor traditional Chinese. Taiwan uses only the traditional form, which uses more character strokes and is therefore more complex.

Of the foreign-born Chinese Americans residing in the United States who speak Chinese at home, only 45% say they speak English very well.⁶

E. Health Care Practices



Developed over thousands of years, Traditional Chinese Medicine (TCM) is guided by a holistic concept of health that emphasizes achieving balance (Yin and Yang) and harmony throughout bodily systems. Qi or Ch'i is a term that the Chinese use to describe the body's "vital energy." TCM aims to restore the balance of Qi or Ch'i using various methods.⁷ Examples of TCM include the use of herbal medicine, acupuncture, cupping, and other modalities. Chinese immigrants are generally knowledgeable about and comfortable with TCM.

It is important to understand the basic methods of TCM because some Chinese Americans and immigrant Chinese may treat a condition with TCM before seeking solutions from Western medicine.⁸

Blending TCM and Modern Medicine:

Both TCM and Western medicine are practiced in mainland China and Taiwan, and most Chinese Americans are comfortable following both medical belief systems.⁹ However, certain areas of health care are seen as better suited for Western medicine, such as emergency care, surgery, and discrete illnesses such as cancer, stroke, and diabetes. Some chronic illnesses, such as arthritis or digestive issues, may be preferentially treated with TCM.

Because TCM emphasizes that each part of the body is interrelated, it should be expected that many Chinese Americans would integrate elements of TCM into the care they receive, including end-of-life (EOL) care. People may design their own therapy, for example, modifying their diet and often seeking assistance from TCM practitioners. Some patients and families may be reluctant to disclose their use of TCM, fearing Western clinicians will disapprove.^{7,8}

Doctors as Authority Figure:

In Chinese culture, doctors are seen as trustworthy, and their opinions are considered very important. Doctors are perceived as intelligent, principled, moral, and possessing specialized knowledge. Elders may feel comfortable deferring to doctors' recommendations over the opinions of their children. Thus, some Chinese elders may deem it unimportant to appoint health care proxies. Sometimes Chinese elders may even request their physicians as their health care proxies, which is not advisable due to potential conflicts of interest. Consensus and harmony among family members is valued, and the opinion of the doctor can impact and guide EOL discussions; however, the opinion of a health care proxy, or 'sole advocate,' may be seen as a barrier to the decision-making process.^{7,10,11}

Respect for Elders:

Filial Piety or "Hsiao" 孝 is a concept that comes from Confucian philosophy. Children feel they have a duty to assist parents and other family members in protecting their health, safety and general well-being, in order to help elders reach longevity.¹⁰

Harmony

Emotional harmony is a major component of the Eastern attitude towards living with peace. Discussing death may be perceived as interfering with inner harmony.^{10,11}

Fatalism:

Many life events are considered unpredictable and uncontrollable. While the Chinese may feel they have some ability to shape the future, the ultimate outcome, such as having a serious illness or experiencing a loss, is often viewed as pre-determined by destiny.¹⁰

F. End-of-Life Cultural Beliefs and Communications



End-of-life (EOL) care is not widely taught in the Chinese community or medical profession.¹² Therefore, for foreign-born Chinese immigrants, the concepts of EOL care may be new or unfamiliar.¹⁰ While talking about advanced care planning (ACP) or death may be 'taboo' within the Chinese culture, there is no evidence that disclosing bad news does harm to Chinese patients.¹³ Also, TCM texts do not ask doctors to avoid talking about death.¹⁰ There are opportunities for Chinese American physicians to engage in more ACP and EOL communication training, so that they can better guide patients in these conversations.^{14,15}

Some barriers to EOL care or ACP discussions include unfamiliarity with the term and practice, lack of access to clear information regarding EOL care options (including hospice care) and decision making, and the superstitious belief that when discussing something bad, it could occur.^{16,17} For example, the Google translation of palliative care is “姑息治疗.” Back translated, the meaning is essentially “Do Nothing Care.” Similarly, the literal Google translation of hospice is “临终关怀”, which means “Last Minute Care.” Is it any wonder that patients whose goals are comfort-oriented end up declining hospice and palliative care once they hear the translated words?¹⁶ The Chinese American Coalition for Compassionate Care (CACCC) has developed a Glossary of End-of-Life Care Terms which translates the English terms into appropriate Chinese terms.¹⁸ Fortunately by 2018, both China and Taiwan have agreed to use these more modernized translations for palliative care (緩和療護) and hospice services (安寧療護). In the U.S., however, the older and archaic Chinese translations continue to be used by nonmedical interpreter services. This is an area of opportunity for improving EOL communication and access for Chinese American populations.

In a survey of 99 Chinese-speaking community-dwelling adults, 45% had heard of the word 'hospice,' but only 21% reported knowing anyone who has used hospice. An encouraging finding was that 94% reported that if their family or friends were seriously ill, they would tell them about hospice services. The vast majority (94%) of respondents reported they would like to receive more information about hospice.¹⁷ Studies have shown that higher education, prior experiences with seriously ill relatives and friends, and residing in the United States for more than 20 years are facilitators of advance directives awareness and discussion.¹¹

G. Attitudes Towards Disclosure of Bad News



Many Chinese families object to telling the patient the truth and doctors often follow the wishes of the families. However, a population study in Hong Kong has shown that most patients wanted the information. This highlights an ethical dilemma in the context of Chinese philosophy, sociological norms, and TCM. However, Chinese views on autonomy and non-maleficence should not justify non-disclosure of the truth. It is recommended that truth-telling should depend on what the patient wants to know and is prepared to know, and not on what the family wants to disclose.¹⁹

A more recent attitudinal survey was conducted in China among 150 pairs of hospitalized cancer patients and their family members. It revealed that significantly more patients than their families believed that patients should be informed of their illnesses (98% vs 67%), should be informed of their conditions completely (69% vs 19%), should be informed as soon as the diagnoses were confirmed (49% vs 15%), and should be informed by doctors (55% vs 11%).¹³

One of the main reasons serious diagnoses are kept from Chinese patients is the fear that the awareness of terminal illness may negatively influence their psycho-spiritual state. A survey conducted of cancer patients in Taiwan found that truth-telling reduced patients' uncertainty and anxiety and did not affect their state of spiritual well-being.²⁰

H. Religion



There are five recognized religions in China – Buddhism, Taoism, Islam, Protestantism, and Catholicism.²¹ Many Chinese Americans practice Christianity, which is more widespread in Taiwan than in mainland China.²² Confucianism, an important moral philosophy that emphasizes ethical behaviors, has greatly influenced beliefs about the appropriate way to live one's life, death and dying.

In mainland China, religion has not been freely practiced for many years due to government policies, though Confucian philosophy has remained widely taught. Therefore, many immigrants from mainland China who have moved to the U.S. may be estranged from religion yet have strong Confucian beliefs. Others may have embraced Protestant Christianity or Catholicism upon coming to the U.S. and this may be an important part of their personal identity. At least one-third of Chinese Americans, especially younger generations, are Christians. This may lead to diverse religious views within families about death and dying.²³

Buddhism, Taoism, and Confucianism all perceive death in a positive and open-minded light. From a cultural respect perspective, it is a good idea to avoid discussing death and dying during the Chinese Lunar New Year period. Beyond that, a traditional Chinese proverb aptly describes the life cycle: “生老病死.” Translated into English, it signifies: “One is born, one ages, one becomes ill, one dies.” Clinicians who care for Chinese American populations should receive appropriate training on discussing ACP and EOL care.

I. Californian AAPI Attitudes, Views and Experiences on Death, Dying, and End-of-Life Care

The California Health Care Foundation (CHCF), a philanthropy based in Oakland, California, has supported efforts to improve serious illness care and end-of-life care since 2007. As part of that work, CHCF has surveyed Californians several times to better understand attitudes and experiences with different aspects of serious illnesses and end-of-life issues. Findings from the two most recent surveys were released in 2012 in *Final Chapter: Californians' Attitudes and Experiences with Death and Dying*, and in 2019 in *Help Wanted: Californians' Views and Experiences of Serious Illness and End-of-Life Care*. Both reports examined areas of consistency or difference among respondents from different racial/ethnic backgrounds, including Asian American/Pacific Islander (AAPI) respondents. While these data are not specific to the Chinese American population, they do provide insight into the larger AAPI population and may dispel some common misconceptions about openness to and interest in addressing issues related to serious illness care and end-of-life care. A three-minute video sharing a story of a Chinese American family's experience with hospice care that accompanies CHCF's survey results can be [viewed here](#).

The 2019 report found:

- **Nine out of ten AAPI respondents** without a serious illness said they would want assistance beyond regular medical care — the kinds of support provided by palliative care — if they had a serious illness. This broad interest was consistently reported across other race/ethnicity groups and different income levels.
- **While there was general agreement on the most important factors at the end of life across racial and ethnic groups**, some factors were more important to some groups. For example, 24% of AAPI respondents said that living as long as possible was “extremely important” to them, compared to 35% of white respondents, 53% of Latino respondents, and 59% of Black respondents. AAPI respondents were also less likely to prioritize being at home and being at peace spiritually compared to the white, Latino, and Black respondents.
- **61% of AAPI respondents** said they would prefer to die a natural death if their heart stopped beating or they stopped breathing, compared to 53% of Black respondents. 13% of AAPI respondents said they would want doctors and nurses to do everything possible to prolong their life; 26% were not sure.
- **76% of AAPI respondents** support California's End of Life Option Act, which gives some terminally ill adults the option to take life-ending medication prescribed by a doctor. This is higher support than Black (70%) and Latino (68%) respondents, and lower than white respondents (82%).
- **AAPI respondents** were the least likely to report having had discussions with their preferred decision maker about the kind of medical care they would want near the end of life – only 30% of AAPI respondents reported having these discussions, compared to 56% of white respondents.

- **Eight out of ten AAPI respondents** say that they would definitely or probably want to talk with their doctor about their wishes for medical treatment toward the end of life if they were seriously ill.
- **91% of AAPI respondents** without a serious illness reported that they would like as much information as possible from their health care provider if they had a serious illness. Results were consistent across other race/ethnicity groups and different income levels.

II. The Coalition Model – Why a Coalition Makes Sense

The Coalition for Compassionate Care of California (CCCC) and the Chinese American Coalition for Compassionate Care (CACCC) share similar grassroots up, top-down approach which strongly relies on forming partnerships and coalitions to support and spread their message about advance care planning and quality end-of-life care. This approach has been successful because coalitions have a broader reach than any single organization, and their members bring expertise, resources and energy that can quickly build credibility and raise awareness of an issue among stakeholders and the community at large.

CCCC and CACCC have each benefited from a strong partnership since 2005. California has a large Chinese American community, and CACCC has been an invaluable partner in developing and sharing advance care planning materials that meet the needs of that community. Because the two organizations share similar goals, they have been able to work synergistically together to build and sustain successful coalitions that help advance the cause.

While each organization has its own distinct culture and experience, there are commonalities in some of the challenges that the coalitions faced and the lessons they learned over the years.

Common Challenges:

- **Gaining attention of stakeholders.** It can be difficult to capture the attention of local stakeholders who have other interests and priorities.
- **Lack of awareness within the community to your issue.** Community stakeholders may lack a basic understanding of your issue, why it is important to them, and the role they can play in addressing or supporting the issue.
- **Limited time and resources of coalition leaders.** Local coalitions are often driven by volunteer leaders who have many competing demands and limited time and resources to devote to the issue. It is an ongoing challenge to keep coalition members actively involved without being overwhelmed.

Lessons learned:

- **Identify local champions.** Look for respected community leaders who share your passion for the issue and have credibility with the audiences you seek to engage.
- **Build a coalition of key stakeholders.** Identify the key stakeholders related to your issue and build a coalition that includes representatives from each of the key groups. Look for groups that are already working together and build on those relationships.
- **Create an independent organization.** As an independent nonprofit organization, local coalitions can serve to bring community competitors together in a forum that supports collaboration and joint problem-solving.
- **Identify community strengths and resources.** To generate continued interest, buy-in, and support, the coalition's initial efforts should focus on activities most likely to be successful in their communities and then build on those accomplishments.
- **Recognize the need for ongoing education.** It will not be enough to have one round of education to inform community members about your issue. Local coalitions should consider establishing speaker's bureaus and education plans for continued outreach and education.

■ **Be patient and persistent.** Effective coalition building and roll-out of a campaign requires coordination and collaboration among a variety of stakeholders—a time-consuming but necessary process.

Long-term success comes from creating a true coalition. It's more than just bringing different organizations together -- it's about creating a collaborative body that moves forward for the greater interest of the larger group and has a shared commitment and vision, as well as individual members with a sense of ownership. It's not just one organization driving things with partners following along.

The Coalition for Compassionate Care of California (CCCC) promotes high-quality, compassionate care for all who are seriously ill or medically fragile. Our goal is to transform health care so that medical care is aligned with individual patient preferences—that people get the care they need and no less, and the care they want and no more. CCCC is a nonprofit statewide collaborative of thought-leaders in health care systems, providers, government agencies, and individuals. Through advocacy, education, and resource development, we are working to ensure that organizations and communities have the information, knowledge, and tools to create the future of palliative care. CCCC is located in Sacramento, California. Learn more at coalitionccc.org or call (916) 489-2222.

III. Outreach Strategies

This section offers outreach strategies and activities that can be used to engage Chinese Americans in your community.

Chinese American Coalition for Compassionate Care

The Chinese American Coalition for Compassionate Care (CACCC) is the first and only coalition in the US devoted to end-of life care for Chinese Americans. The coalition consists of over 300 local, state, and national partner organizations and approximately 3,000 individual members supporting the mission: "To build a community where Chinese Americans are able to face the end of life with dignity and respect."

CACCC's coalition model emphasizes the importance of bringing like-minded people to the table — diverse professionals, community leaders and individuals, and organizations that serve Chinese Americans — and dedicates portions of its meetings to educate coalition members, volunteers and plan projects. For more info, visit caccc-usa.org, email info@caccc-usa.org or call 866-661-5687

A. Assessing Need

Assessing the needs of the Chinese American community regarding end-of-life issues is necessary for designing outreach strategies. In addition, it is crucial to assess the state of knowledge and needs of health care providers who work closely with Chinese Americans, especially Chinese American medical professionals. These providers offer insight into their attitudes towards Traditional Chinese Medicine and Western medicine in relation to end-of-life care. Whether through interviews, focus groups or surveys, the views of providers who serve Chinese Americans provide invaluable insights for outreach initiatives.

The Coalition for Compassionate Care of California (CCCC) completed a needs assessment that sought to elicit Chinese American community's attitudes toward end-of-life care. Sandy Chen Stokes, RN, MSN, CACCC founder, and the NHPCO Diversity Advisory Council Committee conducted focus groups with patients and families as well as with Chinese American doctors who practiced both Eastern and Western medicine. Physicians said one barrier to good end-of-life care is that many Chinese still believe that talking about death will result in an earlier death.

The results of the Chinese American needs assessment led to the development of "Mrs. Lee's Story: Medical Decisions Near the End of Life" with Sacramento Healthcare Decisions. This 16-page booklet is appropriate for patients, families, and clinicians. Written in Chinese and English, it includes basic information on advance care planning, pain management, and hospice care.

B. Provide Education and Training About End-of-Life Care

Consumers need to know about advance care planning, pain management and hospice and palliative care services; providers need to understand how they can better serve the end-of-life needs of the Chinese American community.

Advance care planning is one of the most direct ways to begin EOL outreach with any community. While advance care planning in other communities may begin with family discussions that lead to completing advance directive forms, the reverse process may take place in the Chinese community. There is emphasis in Chinese culture on doing things 'the right way' and following the rules of the health care system. This may offer an opportunity to introduce advance directives as 'the right thing to do' when thinking about illness and death.

The biggest challenge with Chinese participants has always been to get them to open up and share their end-of-life concerns and preferences. CACCC's Heart to Heart® cards, inspired by Coda Alliance's "Go Wish" cards, have helped people discuss end-of-life issues.

CACCC's Heart to Heart cards contain statements in Chinese and English about issues that Chinese consider important in the last days of their lives. This helps them become aware of options they might not think of without a reminder. Special Wish cards (jokers) allow discussion of issues not raised on the cards. Each of the four suits represents a different end-of-life concern. Hearts represent spiritual concerns, diamonds financial issues, clubs social needs, and spades physical necessities. These card games are typically played at Heart to Heart® Café, events where tea and pastries are served and participants are encouraged to discuss end-of-life issues. Participants are surprised that they are able to openly discuss end-of-life issues easily in a Heart to Heart Café setting facilitated by trained volunteers. CACCC's Heart to Heart Café was inspired by the Death Café, an idea out of England that encourages non-structured conversations about death. The Heart to Heart Café has been very successful in the U.S. at encouraging Chinese participants to discuss advance care planning. The café and cards have also become popular in Canada, Taiwan, China, Malaysia, Singapore and Hong Kong.

Trained bilingual Chinese volunteers assist those who want to complete an advance directive. To encourage family involvement, each presentation is followed by another session to give participants an opportunity to discuss and clarify their preferences with their health care proxy. CACCC has translated the California Advance Directive and POLST/MOLST forms into Chinese.

C. Develop and Distribute Helpful Resources

Resources developed by CACCC in collaboration with partner organizations include:

■ Videos on advance care planning, hospice and palliative care, and starting EOL care conversations. Resources developed by CACCC in collaboration with partner organizations include:

- **Advance Care Planning*** <https://youtu.be/JIHbDEj42b8> (4:38)
- **Hospice & Palliative Care*** <https://youtu.be/KyWikiCH7uw> (7:10)
- **Starting the Conversation*** <https://youtu.be/LhwdInpYqsU> (6:18)
- **Advance Care Planning*** (Chinese subtitles) <https://youtu.be/6ZADPH9QCf4> (4:38)
- **Hospice & Palliative Care*** (Chinese subtitles) <https://youtu.be/dzy5N5X8qp4> (7:10)
- **Starting the Conversation*** (Chinese subtitles) <https://youtu.be/lwSERhj8cr8> (6:18)

*Videos produced February 2022 in partnership with UCSF DGIM.

- CACCC translation of **CCCC's Decision Guides** about life-sustaining treatment: CPR, Ventilator, Tube Feeding and Artificial Hydration.
- CACCC translated seven of Conversation Projects **Conversation Starter Kits**
- CACCC modified California Advance Healthcare Directive into Chinese to better-fit Chinese cultural norms. A DVD presentation in Mandarin and its accompanying 50-page booklet in Chinese, *Advance Healthcare Directive & Hospice and Palliative Care*, were developed and distributed free.

- **Loving Life - Understanding Hospice** (DVD)
- **Learning to Let Go: Saying Goodbye Peacefully:** A book about Chinese Americans and their attitudes and choices at the end of their lives, about the personal experiences of patients, family members, volunteers, and health care professionals dealing with end of life and offers insight on a peaceful and guilt-free death.
- The documentary film **"Kathy & Windy"** that features a mother and daughter's journey confronting mortality. Trailer: www.youtube.com/watch?v=D8L9g_YKKoQ

For access to these resources, visit CACCC's webpage, www.caccc-usa.org

D. CACCC Mindful Caregiver Training

During the pandemic, CACCC launched a virtual online program for caregivers. The "Mindful Self-Care for Caregivers" program is an 8-week course for Chinese American family caregivers, volunteers, and health care professionals. CACCC collaborated with Zen Caregiving Project (ZCP) of San Francisco to develop the course, based on ZCP's Mindful Caregiving Education program. The "Mindful Self-Care for Caregivers" consists of seven parts: Mindfulness; Cultivating Compassion; Self-Care; Communication; Healthy Boundaries; Grief, Loss, and Bereavement, and Council: Building Resilience Through Sharing.

In addition to the 8-week course, CACCC conducts a weekly Mindful Caregiving Stress Reduction program. The weekly program has been attended by Chinese Americans from all over the country, for instance: Taiwan, China, Malaysia, Hong Kong and Canada.

E. Cultivate Volunteers

There are not enough Chinese American health care professionals in most communities to meet the needs of their patients and their families. Therefore, training bilingual Chinese volunteers has become a key way to link with communities and improve services.

Coalitions are sustained by trained volunteers, ideally representing the community or groups that the coalition hopes to serve. In addition to cultivating attention to end-of-life care in their community and helping form new relationships, Chinese American volunteers disseminate information, translate documents, and serve as interpreters in health care settings and community outreach programs. Coalition volunteers also enhance the credibility and likely success of community efforts. If you are perceived to be an outside group seeking to do something "to" a diverse community, you are less likely to succeed.

In a hospice setting, the role of trained volunteers is a broad one, from patient care to administrative tasks.

Typically, volunteer training is conducted in a place connected with the Chinese American community. Partnering with a Chinese American community center, Chinese Christian church or Buddhist temple is a good way of demonstrating your commitment to respecting Chinese American culture and building further bridges to the community.

F. Engage the Chinese American Media

To continue to raise awareness of and engage the Chinese American community in end-of-life issues, CACCC cultivated relationships with the Chinese-language media, developing ads and public service announcements, and arranging coverage with local journalists, producers and hosts of radio shows and television programs. Often these outlets have been eager for new content and new story lines.

There are several Chinese-language newspapers that have national distribution in the U.S., as well as regional papers in Florida, California, New Jersey, Chicago and Seattle. There are radio stations that broadcast in Chinese in New York, California, Washington, D.C., and Philadelphia. Finally, there is local television programming in Chinese in New York and California.

IV. Collaborations and Partnership Perspectives

A. University of California, San Francisco Memory and Aging Center (UCSF MAC) – Collaboration with a Medical Center Clinic Setting

Overview:

In this section, we outline outreach strategies that can potentially enhance the engagement of Chinese Americans in your community. The community outreach team of the University of California, San Francisco Memory and Aging Center (UCSF MAC) has committed more than a decade of effort to promote brain health knowledge to regional communities and enhance diversity in dementia research. To date, this outreach program has successfully invited more than 250 Chinese Americans to participate in brain health research. Below are specific strategies that are found to be effective for the outreach efforts at UCSF MAC.

I. Building Complementary Partnership

Understanding the strengths and limitations of your organization and other establishments may amplify the impact of your community outreach efforts. By joining forces with complementary organizations, one could enhance work efficiency, diversify expertise, and expand their reached audiences. These complementary qualities may present in different forms, ranging from varying professional expertise, different community networks, to distinct outreach platforms. A typical example of this nature is the recent collaboration between UCSF MAC and the Chinese-American Coalition for Compassionate Care (CACCC). As a medical research center that studies neurodegenerative diseases, UCSF MAC specializes in brain health, brain aging, and dementia diseases. On the other hand, CACCC is a US-based coalition that offers optimal end-of-life care education and support in advance care planning, palliative care and pain management, and provides training in respite, hospice, grief care and mindful self-care for Chinese Americans. By combining effort, this collaboration aims to (1) Enhance brain health literacy, (2) Increase awareness of dementia and end-of-life issues, and (3) Administer culturally-adapted palliative and hospice care model for the Chinese-American community. This partnership enables both parties to reach out to more Chinese Americans; it also allows them to offer more refined and specialized care to the elder Chinese American. The end-of-life journey for dementia individuals is unlike other diseases.^{23,24,25} For instance, due to the gradual loss of cognitive capacity, advance care planning ideally should begin at the early stage of the disease, and not at the end of the disease course.²³ As dementia progresses, more often than not, the patients and families would develop a strong sense of self-identity loss. Building bereavement support strategies based on the psychological losses and not physical changes, and offering them to both dementia individuals and their loved ones at the early dementia course, are essential to optimize dementia care. Such approaches can be hugely facilitated by combining resources from organizations with different specialties such as UCSF MAC and CACCC.

II. Multidirectional communication model

Enriching your collaboration network's diversity could add stress to the communication fluency in your outreach efforts, as each stakeholder may be accustomed to different work styles. Thus, when working with individuals from

a variety of professions and cultural backgrounds, adopting a multidirectional communication model can vastly enhance communication efficiency and maximize the contributions of different stakeholders. Proactively creating fluid and secure channels for different stakeholders to share knowledge and reflect on challenges can be hugely beneficial, particularly for Chinese Americans that are less outspoken. Most importantly, patients and caregivers should be included in the communication network, so first-hand information is available to reflect the clinical needs and monitor outreach activities' quality. This can be accomplished by distributing regular or post-event surveys, holding open-door events, and forming a community advisory committee. Language barriers should be taken into consideration when establishing communication platforms to maximize responsiveness. Through pre and post-event survey, the UCSF MAC Chinese outreach team has been able to customize many of the educational events based on the audiences' interest and invite many Chinese Americans to participate in brain health research.

III. Knowledge Sharing to Promote Health Literacy and Address Baseless Health Stigma

In traditional Chinese culture, the elders are often referred to as "the wise one". Thus, having conversation topics related to dementia, advance care planning, and end-of-life issues with your elders may be regarded as ominous, disrespectful and/or against the value of filial piety. This is generally due to low brain health literacy and inadequate awareness of the benefits of timely planning discussions. Sharing scientific knowledge on dementia prevention measures can undoubtedly reduce the risk of dementia and benefit the general population from a public health perspective. Additionally, educating the public on the importance of an early diagnosis in dementia and advance care planning can improve the clinical care and quality of life of the elderly Chinese American population.²³ All these can be achieved through educational events and effective information distribution. This information should be delivered in a friendly, accessible, language, and culturally adapted mode, such as Chinese printed materials, in-person/virtual lectures, podcasts, or short video clips conducted in Chinese languages.

In addition to engaging clinical providers to deliver relevant information, inviting community volunteers as ambassadors to share personal experience and advocate for your organization can be hugely helpful. This is because Chinese communities are highly responsive to "word-of-mouth" strategies. You can also consider incorporating interactive training programs to enhance the educational effect. One typical example would be the aging empathy training, in which participants are invited to experience the feelings when their body age, by wearing dark safety goggles, thick gloves and headphones, with the hope to increase empathy and reduce stigma towards aging and/or dementia.

IV. Create Your Image and Identify Platforms that Reach Your Audience

It is important for a community outreach program or organization to define and solidify its image. This begins with identifying your target audience, determining your aims, and developing your key messages. With the fundamentals outlined, you can identify suitable platforms for people to find you and your content. Creating a quality webpage for your organization can serve as a channel to increase legitimacy and boost recognition among your target audiences. Other platforms that may equally serve this purpose include social media, emails, events, radio and television shows, newspaper articles and advertisements, awards, and search engine optimization. This decision should be tailored to your target audience, your funding resources, and the surrounding circumstances. For example, during the COVID pandemic period, the UCSF MAC Chinese outreach team relied more heavily on social media and remote engagement strategies to reach our target population. In the year 2019, it is estimated that 72% of U.S. adults were active social media users, with Facebook (69%) and YouTube (73%) being the most popular online platforms. The user rate in 2019 was consistent across various racial/ethnic groups (71-78%), geographic regions (64-77%), household income levels (68-83%), and education levels (64-80%).²⁶ Even for the 65 and above age group, the percentage of engagement still reached as high as 40%. Therefore, the approach of adopting social media platforms is an ideal strategy to engage the Chinese American elders and circumvent the impact of the COVID pandemic. Since the start of the shelter-in-place policy in California, our team has successfully organized 15 Chinese outreach events, reaching 1,304 audiences that spread across 19 U.S. states and 12 countries worldwide.

V. Accessibility of Available Resources

It is essential to offer useful information and helpful tools for your target population and make it accessible. You can consider sharing these important materials and resources on your webpage or distribute them at local community centers. You may also distribute the materials at events that your target audience would attend, even if the themes of the event are not closely related. The materials should ideally be language and culturally adapted to enhance reader-friendliness. It is also helpful to provide feedback channels to guide the development of these materials. One such example would be the Mandarin and Cantonese educational video series developed by the Chinese outreach team at UCSF MAC. These videos are posted on our webpage, Facebook page, and YouTube channel, and the links are shared with all our community partners. Feedbacks received at the comment sections are documented and summarized for internal reflection purpose. Additionally, web links to express interest in participating in brain health research are made available on our webpage and Facebook page.

VI. Cultivate volunteers

Volunteers that shared common aspirations with your organization are an invaluable force for community outreach effort. They are commonly equipped with the language proficiency and cultural sensitivity essential to attend to the needs of Chinese American patients, caregivers, and families. As there are limited health care providers that are fluent in both Chinese and English language, training volunteers is a feasible strategy to expand outreach. Trained volunteers can help disseminate information, translate materials, and serve as interpreters in community outreach events. Their existing connection with the local community will help establish the credibility of your organization. You can also invite volunteers that have long term commitment to your organization to be part of your planning and executive teams. This helps encourage their continuous engagement, and their feedback can be invaluable for your organization. For the past two years, the UCSF MAC Chinese outreach team has worked closely with the Buddhist Tzu Chi Organization (local Bay area branches) in enriching their volunteers' understanding of the early signs of dementia. Through this effort, we manage to increase brain health literacy and engage more Chinese Americans to volunteer for brain health research. Read more here: memory.ucsf.edu

B. El Camino Health, Mountain View, CA – Volunteer Patient Ambassador Program in a Hospital Setting

El Camino Health (ECH) is a non-profit hospital with 420 beds based in Mountain View and Los Gatos, California, with additional satellite clinics in the Silicon Valley.

El Camino Health provides several unique volunteer opportunities. Spiritual Care volunteers assist the hospital's professional chaplain by making assigned rounds to patients, families and staff. The volunteer becomes an additional referral source to alert the chaplain of follow-up needs a patient or family may have. The goal is to create an environment where spiritual, emotional and physical healing can occur.

The Chinese American Coalition for Compassionate Care (CACCC) is a critical resource for El Camino Health as it provides a steady stream of trained volunteers for our Patient Ambassador Program since 2014. As an illustration, for the 2019 calendar year, 14 Patient Ambassadors contributed a total of 441 volunteer hours visiting 1,087 patients. During the 2020 calendar year 1/1/20 - 3/3/20, prior to the COVID-19 pandemic shut down, the number of volunteer hours totaled 84, with 200 patient visits.

Patient Ambassador Volunteers provide patient and family-centered care and enhance community satisfaction by offering emotional and culturally appropriate support to all El Camino Hospital nursing departments that care for patients whose preferred language is Chinese (Cantonese, Mandarin, or Taiwanese). In addition to providing emotional support, Ambassadors provide approved information on available resources and escalate patient and/or family concerns to appropriate staff members for follow up.

Recognizing that demand for this service fluctuates, it is preferred that volunteers be available for a minimum one half-day shift (morning or afternoon) commitment. **Specific responsibilities include:**

- Assisting clinical staff in orienting patients and their family members to El Camino Health, informing them of visitor policies, familiarizing them to basic items in the room, and communicating care needs in their preferred language.
- Serving as a non-clinical liaison between the patient, family, and caregivers.
- Alerting staff to concerns, increasing anxiety, cultural customs, or other matters that may require attention.
- Assessing needs of patients and family members from a variety of cultural, ethnic, and religious backgrounds.
- Acquainting and assisting patients and family members with our Healing Arts program and other available hospital resources, such as the Health Library.

Patient Ambassador Candidates are to be mature individuals with excellent communication skills and possess the ability to work independently while maintaining patient confidentiality at all times. It is essential that they be able to relate tactfully and objectively to patients and families in crisis and maintain healthy boundaries. State and Federal mandates require that one be able to observe confidentiality. **Beyond this, Candidates must:**

- Learn and demonstrate the El Camino “We-Care” Excellence Standards; Be comfortable in a hospital setting; and be proficient in English and other languages preferred.

ECH Volunteer Patient Ambassadors, share their extraordinary stories of how their respective compassionate caring have impacted the lives of the patients and families they have the privilege to serve. Click on the link to read their personal stories in Chinese.

C. Metropolitan Jewish Health System (MJHS) Hospice and Palliative Care, Brooklyn, NY – The Benefit of Using Chinese-Speaking Volunteers with Patients and Families at the End of Life in a Hospice Setting

Since 1907, MJHS has been one of the largest nonprofit health systems in the greater NY area, providing home care, hospice and palliative care for adults and children, rehabilitation and nursing care and Elderplan Medicare and dual-eligibility health plans. MJHS has also created the MJHS Institute for Innovation in Palliative Care to address the emerging need for specialist-level community-based palliative care and is committed to promoting access to such through innovation, scientific inquiry, quality improvement and professional education.

Challenges in providing care to the Chinese-speaking community

While MJHS provides culturally sensitive care to its Chinese patients, it is difficult to match every Chinese patient to a team clinician speaking their specific language or dialect. Frustration and concerns are frequently expressed by both English-speaking staff relying on the language line to hold sensitive end-of-life discussions as well as Chinese-speaking patients or families who cannot understand the breadth of hospice services or the details of their own hospice care. Often, Chinese community members are also afraid of accessing hospice care because of prevalent myths that it hastens death and their concerns about safety and trust.

Organizational best practices to support Chinese-speaking patients and families

It is most beneficial for the Chinese patient population to have access to appropriate ambassadors who can bridge language and cultural barriers and relay vital information from the hospice care team. Hospice volunteers are

already trained to support hospice patients and, therefore, can easily serve as such ambassadors. Engaging in goals of care discussions which may include evaluating appropriate care settings and care plans are less frightening when language proficient volunteers who share the same norms and taboos help create a safe space for the patient. Identifying and collaborating with culturally specific organizations in outreach and recruitment in the Chinese community has led to the collaboration with the Chinese American Coalition for Compassionate Care (CACCC).

The collaboration between CACCC and MJHS Hospice and Palliative Care

In just six (6) months (October 2019 to March 2020), four (4) Chinese-speaking volunteers received training from CACCC and MJHS and subsequently joined MJHS Hospice and Palliative Care. Collectively they provided 293 volunteer hours to 16 patients.

Volunteers freely give their time and energy and bring commitment, compassion and a sense of pride to volunteering within a supportive team. All its members, including the volunteer, work closely together to fulfill the needs of the patients, their families and the agencies.

The impact of Chinese-speaking volunteers

In addition to gaining great personal gratification from serving patients during a vulnerable time, the volunteers serve as a bridge between clinicians, the Chinese-speaking patients and their families, allowing for the delivery of culturally appropriate and sensitive care. Through social interaction, the volunteers build relationships that brighten someone's day; it's an opportunity to make an individual happy with just being a "friend" and support. The link below is an article in Chinese by Jen Chan, a Chinese-speaking MJHS hospice volunteer, who describes the impact her volunteering has had on the patients and herself: The volunteers' extensive support, deep connections and valued friendships are maintained by regular phone calls. At MJHS, it's always about caring - every minute, every day. For more information about MJHS, visit mjhs.org.

V. Resources for Community Engagement

A. Warmline:

CACCC Toll-free Warm Line: 1-866-661-5687. Leave a message and a CACCC staff or trained volunteer will contact you within 24 hours.

B. Educational Tools

- **English CACCC Chinese Educational Materials:** cacc-usa.org/en/resource/documents.html
- **Chinese CACCC Chinese Educational Materials:** cacc-usa.org/ch/resource/documents.html

C. Professional Organizations

- **AARP 樂齡會™:** chinese.aarp.org
An excellent resource site for seniors, older adults and family caregivers for information in Chinese with English translation option.
- **ACC Senior Services, Sacramento CA:** www.accsv.org
A longtime CACCC partner since 2005, ACCSV's mission is to promote the general welfare and enhance the quality of life for our community by identifying, developing, and providing culturally sensitive health and social services for older adults.
- **Alhambra Hospital:** www.alhambrahospital.com
Alhambra Hospital Medical Center strives to become one of the leading hospitals in the San Gabriel Valley by providing safe, integrated, affordable patient care and services, which will promote the health and well-being of our patients and our community.
- **Alzheimer's Association:** www.alz.org/norcal/about_us/everyone-is-welcome/chinese_page
The Alzheimer's Association Northern California and Northern Nevada Chapter provides support, education, training, and other resources to increase knowledge and to support those facing Alzheimer's disease and other dementias. This link is for Chinese resources.
- **Chinese American Coalition for Compassionate Care (CACCC):** cacc-usa.org
The first and only coalition in the United States dedicated to improving end-of-life care for Chinese Americans. See page 11. Email info@cacc-usa.org or call 1-866-661-5687.
- **Coalition for Compassionate Care of California (CCCC):** coalitionccc.org
See page 10. CCCC is located in Sacramento, California. Call (916) 489-2222.
- **El Camino Health – Chinese Health Initiative:** www.elcaminohealth.org/services/chinese-health-initiative
The Chinese Health Initiative (CHI) enhances the health and well-being of our Chinese community members. Through partnership with the hospital and other organizations, we offer specialty programs that promote awareness and prevention of health conditions that commonly affect the Chinese population.

■ **Family Caregiver Alliance:** www.caregiver.org

Family Caregiver Alliance has information available in Chinese covering a variety of topics such as Alzheimer's disease, assisted living, caregiving, stroke, and advance care planning.

■ **Hospice Foundation of Taiwan:** www.hospice.org.tw

Hospice Foundation of Taiwan was established in 1990 by MacKay Memorial Hospital and Shuanlien Presbyterian Church in 1990. It is the first NPO in Taiwan advocating for hospice and palliative care.

■ **Li Ka Shing Foundation Heart of Gold National Hospice Service Program:** lksf.org/initiative-project/heart-of-gold-national-hospice-service-programme

Founded by Li Ka Shing Foundation (LKSF), 40 Hospice Units were established since 1998, more than 30 Units currently in operation, in 30 cities of 29 provinces in mainland China and 10 Hospice Units in Hong Kong. Serving over 228,000 patients.

■ **Mental Health Association for Chinese Community (MHACC):** www.mhacc-usa.org

MHACC's mission is to raise awareness of mental health within the Chinese community through advocacy, education, research, support, and services to represent the wide spectrum of Chinese families and individuals affected by mental illness.

■ **MJHS Hospice and Palliative Care:** www.mjhs.org

MJHS is one of the largest not-for-profit health systems in the region. Our range of health care services include home care, hospice and palliative care for adults and children, two skilled centers for rehabilitation and nursing care.

■ **New York Presbyterian-Queens (NYPQ):** www.nyp.org/queens

NYPQ is one of the nation's most comprehensive, integrated academic health care systems, from dependable primary care to the most sophisticated specialties. Located in Flushing, New York, you have access to outstanding care from Weil Cornell Medicine Physicians.

■ **On Lok:** www.onlok.org

On Lok empowers older adults to age with dignity and independence. With nearly 50 years of experience, On Lok is a trusted resource in San Francisco, Santa Clara County, and the Tri-City area of Alameda County.

■ **Self-Help for the Elderly:** www.selfhelpelderly.org

Self-Help for the Elderly promotes independence, well-being, and dignity for older adults through culturally aligned services and programs in the San Francisco Bay Area.

■ **Tzu Chi Foundation, USA:** tzuchi.us

Active in five continents, Tzu Chi has provided relief aid to over 100 countries and areas globally, the Tzu Chi Foundation provides services for those of any cultural or religious background with medical, educational, humanistic culture, disaster relief needs, and environmental protection.

■ **University of California, San Francisco Memory and Aging Center (UCSF MAC):** memory.ucsf.edu

The mission of UCSF MAC is to provide the highest quality of care for individuals with cognitive problems, to conduct research on causes and cures for degenerative brain diseases, and to educate health professionals, patients and their families.

D. Advance Directive & POLST/MOLST

■ **California AHCD & POLST: CACCC:** caccc-usa.org/forms.html **CCCC:** coalitionccc.org

■ **CaringInfo Advance Directives by state:** www.caringinfo.org/planning/advance-directives/by-state

■ **Five Wishes™:** agingwithdignity.org

■ **National POLST/MOLST by state:** polst.org/state-programs

■ **PREPARE for Your Care:** prepareforyourcare.org/en/advance-directive

***Note:** Please check whether the documents listed above are legally valid in your state since some state statutes do not recognize translated versions of advance directives.

VI. Acknowledgements

Chinese American Coalition for Compassionate Care (CACCC)

Shingle Springs, CA

Sandy Chen Stokes, RN, MSN

Shirley Pan

Jeanne Wun

California Health Care Foundation (CHCF)

Sacramento, CA

Kate Meyers, MPP

Coalition for Compassionate Care of California (CCCC)

Sacramento, CA

Judy Thomas, JD

Kelley Queale

El Camino Health (ECH)

Mountain View, CA

Rev. John Harrison

MJHS Hospice and Palliative Care (MJHS)

Brooklyn, NY

Toby Weiss

Carrie Chan

Jen Chan

Miryam Rabner

NewYork-Presbyterian Queens

Flushing, NY

Cynthia X. Pan, MD, FACP, AGSF

Christine Feng, MD

National Hospice and Palliative Care Organization Diversity Advisory Council (NHPCO DAC)

Alexandria, VA

UCSF Memory and Aging Center (UCSF MAC)

San Francisco, CA

Boon Lead Tee, MD

VII. Appendix

Chinese American Coalition for Compassionate Care 美華慈心關懷聯盟
English/Chinese Glossary of End-of-Life Care Terms 生命末期療護詞彙

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 简体中文
active dying	瀕死	濒死
addiction	上癮	上瘾
advance care planning	事前療護計劃	事前疗护计划
advance health care directive/ advance directive	醫療照護事前指示	医疗照护事前指示
agitation	躁動	躁动
antibiotics	抗生素	抗生素
antidepressant	抗憂鬱藥	抗忧郁药
antipsychotic drugs	抗精神病藥物	抗精神病药物
anxiety	焦慮	焦虑
apnea	呼吸暫停	呼吸暂停
aromatherapy	芳香療法	芳香疗法
art therapy	藝術療法	艺术疗法
artificial nutrition and hydration	人工營養及水份補充	人工营养及水分补充
autonomy	自主權	自主权
autopsy	驗屍	验尸
bedsore/pressure sore	褥瘡/壓瘡	褥疮/压疮
benefit versus burden	利益vs負擔	利益vs负担
benign	良性	良性
bereavement	傷慟/喪慟	伤恸/丧恸
bioethics	生命倫理	生命伦理
bladder distention	膀胱膨脹	膀胱膨胀
blood transfusion	輸血	输血

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 簡體中文
bowel obstruction	腸阻塞	肠阻塞
brain death	腦死	脑死
cardiac arrest	心臟停止跳動	心脏停止跳动
cardiopulmonary resuscitation (CPR)	心肺復甦術	心肺复苏术
caregiver	照顧者	照顾者
catheter	導管	导管
chaplain	靈性輔導師	灵性辅导员
code status	急救意願	急救意愿
coma	昏迷	昏迷
comfort care	舒適療護	舒适疗护
communication	溝通	沟通
congestive heart failure	充血性心衰竭	充血性心衰竭
constipation	便秘	便秘
convulsion	抽搐/痙攣	抽搐/痉挛
coroner	法醫/驗屍官	法医/验尸官
COVID-19	新冠病毒	新冠病毒
cramps	抽筋	抽筋
cyanosis	皮膚發紫	皮肤发紫
death and dying	死亡及瀕死	死亡及濒死
death rattle	瀕死時的喉音	濒死时的喉音
delirium	譫妄	谵妄
dementia	失智症	失智症
depression	憂鬱	忧郁
diagnosis	診斷	诊断
do not intubate (DNI)	不做氣管內插管	不做气管内插管
do not resuscitate (DNR)	不做急救	不做急救
drug tolerance	耐藥性	耐药性

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 簡體中文
dysphagia	吞嚥困難	吞咽困难
dyspnea	呼吸困難	呼吸困难
edema	水腫	水肿
emergency room/department	急診室	急诊室
emesis/vomiting	嘔吐	呕吐
empathy	同理心	同理心
end-of-life care	生命末期療護	生命末期疗护
End of Life Option Act	生命終結選擇權法案	生命終結选择权法案
ethical dilemma	倫理兩難困境	伦理两难困境
euthanasia	安樂死	安乐死
fatigue	極度疲倦	极度疲倦
goals of care	療護目標	疗护目标
grief	哀傷	哀伤
guided imagery	引導想像/想像治療	引导想象/想象治疗
hallucinations	幻覺	幻觉
health care provider	醫療提供者	医疗提供者
healthcare agent/proxy/power of attorney	醫療代理人/法定代理人	医疗代理人/法定代理人
hematuria	血尿	血尿
hemorrhage	出血	出血
hospice care	安寧療護	安宁疗护
infection	感染	感染
informed consent form	知情同意書	知情同意书
insomnia	失眠	失眠
intubation	氣管內插管	气管内插管
isolation	隔離	隔离
jaundice	黃疸	黄疸
kidney dialysis	洗腎/血液透析術	洗肾/血液透析术
laxative	輕瀉劑/通便藥	轻泻剂/通便药

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 简体中文
life-threatening	生命威脅	生命威胁
living will	生前預囑	生前预嘱
long term care	長期療護	长期疗护
malignant	惡性的	恶性的
Medicaid/Medi-Cal	州/加州醫療保險;白卡	州/加州医疗保险;白卡
medical decision-making capacity	醫療決定能力	医疗决定能力
medical futility	醫療無效	医疗无效
Medical Orders for Life-Sustaining Treatment (MOLST)	維持生命治療醫囑	维持生命治疗医嘱
Medical record	醫療紀錄	医疗记录
Medicare	聯邦醫療保險 ; 紅藍卡	联邦医疗保险; 红蓝卡
medicine	藥物	药物
memory loss	記憶喪失/失憶	记忆丧失/失忆
metastasize	(癌症) 轉移	(癌症) 转移
mindful/mindfulness	正念	正念
monitor	監測器	监测器
mood swings	情緒波動	情绪波动
morphine	嗎啡	吗啡
mottling	皮膚紅紫斑	皮肤红紫斑
mourning	哀悼	哀悼
muscle spasm	肌肉攣縮	肌肉挛缩
music therapy	音樂療法	音乐疗法
natural death	自然死	自然死
nausea	噁心	恶心
next of kin	近親	近亲
nursing home	護理之家/療養院	护理之家/疗养院
occupational therapy	職能治療	职能治疗
ombudsman	監察員/申訴員	监察员/申诉员

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 簡體中文
operation	手術	手术
organ donation	器官捐贈	器官捐赠
oxygen/ oxygen tank	氧氣/氧氣筒	氧气/氧气筒
pain management	疼痛控制	疼痛控制
palliative care	緩和療護	缓和疗护
paralysis	癱瘓/麻痺	瘫痪/麻痹
pass away	去世	去世
patient-centered care	以病人為中心的療護	以病人为中心的疗护
patient-controlled analgesia (PCA)	病人自控止痛	病人自控止痛
physical therapy	物理治療	物理治疗
Physician Orders for Life-Sustaining Treatment (POLST)	維持生命治療醫囑	维持生命治疗医嘱
physician-assisted-dying/physician-aid-in-dying	醫師協助死亡	医师协助死亡
post-traumatic stress disorder (PTSD)	創傷後壓力症候群	创伤后压力症候群
pre-existing condition	(保險前)已存在的病況	(保险前)已存在的病况
prescription drug	處方藥	处方药
privacy	隱私	隐私
prognosis	預後/病情進展	预后/病情进展
prolonging dying	延長瀕死期	延长濒死期
pulmonary edema	肺水腫	肺水肿
pulse oximeter	脈搏血氧儀	脉搏血氧仪
quality of life	生命品質/生活質量	生命品质/生活质量
quarantine	隔離	隔离
radiation therapy	放射治療	放射治疗
registered nurse	註冊護士	注册护士
rehabilitation medicine	復健醫學	复建医学
relaxation technique	放鬆技巧	放松技巧
religious belief	宗教信仰	宗教信仰

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 簡體中文
renal failure	腎衰竭	肾衰竭
respiratory arrest	呼吸停止	呼吸停止
respiratory failure	呼吸衰竭	呼吸衰竭
respite care	喘息療護	喘息疗护
restlessness	躁動	躁动
sedation	鎮靜劑	镇静剂
seizure	癲癇	癫痫
self-care	自我照顧	自我照顾
serious illness	嚴重疾病	严重疾病
shock	休克	休克
side effect	副作用	副作用
sleeping pill	安眠藥	安眠药
social worker	社工師	社工师
spiritual care	靈性照護	灵性照护
stool impaction	大便阻塞	大便阻塞
surgery	手術/開刀	手术/开刀
symptom	症狀	症状
thrush	口瘡	口疮
titration	(給藥時的) 劑量調整	(给药时的) 剂量调整
tracheostomy	氣切	气切
Traditional Chinese Medicine (TCM)	傳統中醫	传统中医
tranquilizer	鎮靜劑	镇静剂
trauma	創傷	创伤
tremor	顫抖	颤抖
tube feeding	管餵食	管喂食
tuberculosis (TB)	肺結核病	肺结核病
tumor	腫瘤	肿瘤

English 英文	Traditional Chinese 繁體中文	Simplified Chinese 简体中文
unattended death	無醫師在場見證的死亡	无医师在场见证的死亡
urinary retention	尿滯留	尿滯留
urinary tract infection (UTI)	尿道感染	尿道感染
urine incontinence	小便失禁/尿失禁	小便失禁/尿失禁
ventilator	呼吸器	呼吸器
vomiting/emesis	嘔吐	呕吐
water retention	水份積留	水分积留
witness	見證人	见证人

References

1. US Census Bureau. (2019). Quick Facts – Population. Available at www.census.gov/.
2. Pew Research Center: Chinese in the US fact sheet. Pew Research Center, 2017a. www.pewsocialtrends.org/fact-sheet/asian-americans-chinese-in-the-u-s (Last accessed Oct 14, 2020).
3. Pew Research Center: Key facts about Asian Americans, a di-verse and growing population. 2017b. www.pewresearch.org/fact-tank/2017/09/08/key-facts-about-asian-americans (Last accessed Oct 14, 2020).
4. Xiang, Biao. 2016. Emigration Trends and Policies in China: Movement of the Wealthy and Highly Skilled. Transatlantic Council on Migration, A Project of the Migration Policy Institute. February.
5. Goodkind A: The Chinese Diaspora: Historical Legacies and Contemporary Trends. www.census.gov/content/dam/Census/library/workingpapers/2019/demo/Chinese_Diaspora.pdf Washington, DC: U.S. Census Bureau, 2019, pp. 1–22. (Last accessed October 14, 2020).
6. Salimbene, S. (2005). Providing culturally-sensitive healthcare to patients of Asian Origin. In *What Language Does Your Patient Hurt In? A Practical Guide to Culturally Competent Patient Care* (2nd ed.). Amherst, MA: Diversity Resources, Inc.
7. Wu, Amy P.W., Burke, Adam, LeBaron, Samuel. (2007) Use of Traditional Medicine by Immigrant Chinese Patients. Available at *Family Medicine* Vol 39 No 3 pp. 195-200.
8. Pan CX, Kushner Kow J. Older Chinese Americans. In: Adler RN, Kamel HK (Eds). *Doorway Thoughts: Cross-Cultural Health Care for Older Adults*. Vol 1. Jones and Bartlett Publishers. 2004. Pp 94-107.
9. Bowman, K.W., Singer, P.A. (2001). Chinese Seniors' Perspectives on End of Life Decisions. *Social Science & Medicine*, 53(4): 455-464.
10. Jia Z, Leiter RE, Yeh IM, Tulsy JA, Sanders JJ. Toward Culturally Tailored Advance Care Planning for the Chinese Diaspora: An Integrative Systematic Review. *J Palliat Med*. 2020 Sep 29. doi: 10.1089/jpm.2020.0330. Epub ahead of print. PMID: 32991239.
11. Wang, X.S., Li, J.D., Reyes-Gibby, C.C., Guo, H., Liu, S.J., Cleeland, C. (2004) End-of-Life Care in Urban Areas of China: A Survey of 60 Oncology Clinicians. *Journal of Pain and Symptom Management*, 27(2), 125-131.
12. Li J, Yuan XL, Gao XH, et al. Whether, when, and who to disclose bad news to patients with cancer: a survey in 150 pairs of hospitalized patients with cancer and family members in China. *Psychooncology* 2012 Jul;21(7):778-84.
13. Chi H-L, Cataldo J, Ho EY, Rehm RS. Please Ask Gently: Using Culturally Targeted Communication Strategies to Initiate End-of-Life Care Discussions With Older Chinese Americans. *American Journal of Hospice and Palliative Medicine*®. 2018;35(10):1265-1272. doi:10.1177/1049909118760310
14. VitalTalk www.vitaltalk.org/
15. Pan CX. Lost in Translation: Google's Translation of Palliative Care to 'Do-Nothing Care.' Blog post May 20, 2019. geripal.org/lost-in-translation-googles-translation-of-palliative-care/

16. Pan CX, Pan CX, Abraham O, Giron F, LeMarie P, Pollock S. Just Ask: Hospice Familiarity in Asian and Hispanic Adults. *J Pain Symptom Management*. 11 Dec 2014;49(5):928-33. PMID: 25499419.
17. CACCC English/Chinese End-of-Life Care Glossary: caccc-usa.org/en/educationmat.html
18. Cy, T., Chong, A., Sy F. (2003) Breaking Bad News: A Chinese Perspective. *Palliative Medicine*, 17:339-343.
19. Kao CY, Cheng SY, Chiu TY, et al. Does the awareness of terminal illness influence cancer patients' psycho-spiritual state, and their DNR signing: a survey in Taiwan. *Jpn J Clin Oncol*. 2013 Sep;43(9):910-6.
20. Taiwan Government Information Office. (2018). A Brief Introduction to Taiwan: Religion. Available at www.taiwan.gov.tw/about.php. (Last accessed March 24, 2022).
21. 2019 Report on International Religious Freedom: China (includes Tibet, Xinjiang, Hong Kong and Macau). Available at www.state.gov/reports/2019-report-on-international-religious-freedom/china/ (Last March 24, 2022).
22. Carnes, T. and Fenggang, Y. (2004). *Asian American Religions: Making and Remaking of Borders and Boundaries*. New York: New York University Press.
23. Bamford, C., et al., *What enables good end of life care for people with dementia? A multi-method qualitative study with key stakeholders*. *BMC Geriatr*, 2018. 18(1): p. 302.
24. Lee, R.P., et al., *End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice*. *PLoS One*, 2017. 12(6): p. e0179355.
25. Poole, M., et al., *End-of-life care: A qualitative study comparing the views of people with dementia and family carers*. *Palliat Med*, 2018. 32(3): p. 631-642.
26. Center, P.R. *Social Media Fact Sheet*. 2019. www.pewresearch.org/internet/fact-sheet/social-media



NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org