PALLIATIVE CARE AND OUR COMMUNITY

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"The remedy for dirt is soap and water. The remedy for dying is living."

– CHINESE PROVERB

The essence of Palliative Care Medicine is to provide care to patients with the goal to relieve suffering. On the surface, it seems that for health care providers, providing relief of discomfort is what each of us do on a daily basis, and is the basic reason we chose to dedicate our careers to medicine.

However, understanding our own cultural challenges has been a unique obstacle for those of us in the Chinese Community. Generally and historically, the topic of end of life has been taboo for our patients. It's considered "unlucky" and any discussion of death or illness is the harbinger of bad fortune. In 2020, AAMG, which currently serves a predominantly Chinese demographic, had only 2% of its patients with CPT codes for Advanced Care Planning (ACP). Also, in a 2021 survey by the Learning Journeys Chinese Workgroup of 230 Chinese Seniors, only 1/3 had any familiarity at all with the concept of ACP. Clearly we need to do better, but how? Perhaps consideration of some differences between Chinese and Western attitudes may be a helpful place to start.

First and foremost, **Filial Piety** is a core value closely held by many of Chinese heritage. Based in Confucianism, filial piety is a moral principle that is deeply rooted in Chinese traditions. Loosely, it's described as respect and responsibility to care for one's parents, but it is far more complex than that. Intertwined are feelings of obligation, devotion and self-sacrifice. Whereas in Western culture, it seems that youth and individualism are important attitudes, in Asian cultures, respect and responsibility for one's elders are key values.

Also, the importance of family cannot be underemphasized. Frequently, Bay Area Chinese households have more than one generation living under one roof. Thus, when decisions are to be made, we must be prepared to look through the lens of the family and caregivers. Clearly there tends to be an interdependence among Chinese family members and a tendency to make decisions as a family instead of individually. Interestingly, our medical training mandates honesty in providing information to our patients. However, it remains common with a substantive diagnosis, for children to request that doctors don't tell their parents; a notion abhorrent to Western providers. But from the perspective of the elder, the attitude is often to let their kids make the decisions. "They know what I want" under this subtext of filial piety. And a sense of obligation from the children may lead to the desire to "never give up." In fact, it is not unusual that there is social pressure from extended family members placed on these dutiful children to choose curative options at the expensive of quality of life. A decision other than that may be seen as a dereliction of their duty.

Moreover, our Chinese population is often uninformed of the availability of palliative and hospice care. Many of these elderly are monolingual first generation immigrants and have limited knowledge of these concepts. Further complicating the situation are issues common to other ethnic communities including a poor understanding of illnesses or procedures, language difficulties, and lack of culturally sensitive providers/services. In addition, physicians must accept that many of our patients utilize Traditional Chinese Medicine adjunctively with Western modalities.

These cultural differences have been recognized by many and there have been some recent successes in the Bay Area. The Chinese American Coalition for Compassionate Care has a program utilizing a deck of cards whereby each card indicate a Senior's wishes as a communication tool to open discussion with their family. They conduct seminars called "Heart to Heart Café". This tool has seen success particularly among Mandarin speaking Chinese in the South Bay. There is useful guidance on their website: www.cacc-usa.org.

Similarly, we have been involved with the Learning Journeys Workgroup (sponsored by the Stupski Foundation) to improve the prevalence of ACP in the San Francisco Chinese Community. Through this collaborative effort of community-based organizations, a new method was developed. Focus groups showed us that the best approach starts with a video story to spark thinking about ACP. We borrowed from a Cantonese Hong Kong production utilizing a popular actor who resonated with a majority of our audience, recognizing him as "an old friend." We follow with a comic pamphlet based on a Chinese traditional concept that dates back thousands of years—**The Five Blessings** (longevity, wealth, health and composure, love of virtue, and good death). Participants go through the brochure with the life journey of the main character, Grandma Blessing. She talks about such things as: What brings you the most joy and happiness? What are some good memories you would like to leave to your family and loved one? And finally, What does a 'good death' look like to you? Eventually, Grandma Blessing introduces the concept of advance care planning. Since our patients love swag, we also produce series-based giveaways such as mugs and pillows for participants to have a reminder of this discussion. These initial seminars are followed by individual community counseling efforts. AAMG is currently expanding this outreach with the aid of Self-Help for the Elderly.

Many hospitals today have developed palliative care teams. According to the Center to Advance Palliative Care, more than 77% of California hospitals now have a palliative care team.

These teams maybe comprised of palliative care specialists, specialized RNs, social workers, physical therapists, chaplains, volunteers and even acupuncturists reflecting the multidisciplinary needs and complexity of caring for patients with serious illness. Many studies have now confirmed that palliative care is associated with better quality of life, better patient satisfaction, less depression, better symptom management and even longer survival. In our community, the Chinese Hospital has its own culturally sensitive team with outreach through its health resource center and its clinics. Sutter Health offers a service called Advance Illness Management (AIM) which accepts referrals for outpatient consults as well as home services. The palliative care team will evaluate the patient and determine qualification to the service and form a care plan for the patient. Further, our community PCPs, performing Advance Care Planning, are integral to preparing patients for the future. ACP can be performed over many clinical visits. We ask our doctors to revisit routinely as a patient ages or their health status changes. Culturally sensitive providers allow patients to have the opportunity to share their values, their preferences for medical care and their desires for future care. It is also a good opportunity to provide a health care proxy and completing a POLST.

Lastly, since the fastest growing segment of our population is seniors over 65, a larger percentage of the population will be living with chronic illnesses. At the community level, we see a need to bridge communication gaps; between providers and patient, between patient and family, and to understand that families are a major part of the decision process. But much work is left to be done within the Chinese Community. A respect of patient dignity, recognition of Asian mores, and a culturally sensitive approach are invaluable. Going forward, we advocate for earlier intervention and more personal care. Ultimately, this process should be self-sustaining as patients utilize fewer futile modalities. Frequently, cognizance leads to more realistic choices, fewer trips to the hospital, less unnecessary chemotherapy, and a higher likelihood to be enrolled in palliative or hospice care at the end of life.

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