Listening, Learning and Living: End-of-Life Care in Chinese-American Communities

VNS Health Hospice Clinicians Take a Moment to Reflect During National Nurses Month and AAPI Heritage Month

Nurse Savi Isinkaunan remembers sitting with one of her hospice patients, an Asian immigrant in New York City, when Savi needed to reach out and call the patient's adult daughter, who lived thousands of miles away back in their home country. Nearing the end of life, the patient could no longer communicate, but Savi was there to help. Savi wanted to discuss end-of-life plans with the family member, but the daughter was struggling. Knowing her mother was in her final days, unable to communicate and so far away, was daunting—and brought forth a mix of emotions, including frustration, fear, and sadness.

Savi calmly asked the family member, "Just imagine you're here with us right now, and that your parent is part of this conversation—what do you think your mother would want?" Savi noticed an immediate change in the daughter's voice, and a certain calm as the conversation went on. "It's in those moments when family members really 'get it'—the idea that hospice, and the care we're providing is very much about quality of life, and people making choices that are best for them," said Savi.

As a hospice nurse with the home and community health nonprofit <u>VNS Health</u>, Savi is intimately familiar with this

dynamic. In addition, as an immigrant herself to the U.S. from Taiwan, she also understands the challenges of being far away from family, and the cultural differences at hand. These differences often extend to basic awareness of hospice care and its benefits. The National Hospice and Palliative Care Organization (NHPCO) noted in their recently published resource guide that many foreign-born Chinese-Americans are not familiar with hospice or EOL planning.

"People are always grateful when you can communicate with them in the same language, and there are also cultural norms and taboos to be mindful of," said Savi. "While some cultures are straightforward about discussing issues related to dying, for many Chinese-Americans, this isn't always the way it is usually done, so families sometimes struggle to discuss end-of-life plans."

In an accompanying survey of Chinese-Americans, NHPCO found that "45% had heard of the word 'hospice,' but only 21% reported knowing anyone who has used hospice." However, survey respondents also showed a willingness to learn more about hospice, with 94% saying that if their family or friends were seriously ill, they would tell them about hospice services.

Ling Wai-Fung, a hospice social worker with VNS Health, also serves Manhattan's Lower East Side and Chinatown, and has seen firsthand how important it is to carefully navigate end-of-life care with families of different backgrounds. Ling notes that as an immigrant himself, having moved to the United States 40 years ago from Hong Kong, he is more familiar with some of the social etiquette that clinicians should be aware of with Chinese families and hospice patients, especially when they first meet.

"Chinese families are almost always very welcoming when we first visit," said Ling, "but it's also important to be aware that you can't just jump into talking about medical care, as that's considered unusual." He notes that when he walks into a patient's home, he is mindful to keep an eye out to see if they have lots of family photos, or if they have religious symbols around the home, all little messages that can help him better meet the patient where they're at.

Connecting can involve something as simple as knowing what holidays and traditions to be aware of. "I always schedule any planned away time during Chinese New Year, because I know families are less likely to want a visit from clinicians during that time," Ling said. "During Chinese New Year, it's considered very bad luck to speak about illness or death, so we have to be as respectful as possible of those beliefs."

Savi and Ling both note that patients are grateful when they can speak with them in their native language, helping them parse complicated medical jargon or navigate paperwork. And beyond physical care, families are also eager to know what kind of spiritual and mental health support is available. As recent reporting found, 63% of Asians, more than any other ethnicity, said they would want emotional support services when considering end-of-life plans.

The two clinicians add that their clients are glad they can learn more about what hospice care entails, and that their team is there to have those conversations and answer any questions patients may have about end-of-life care. "One patient of mine and his daughter wanted to know what prognosis his doctors had for him, and I explained that though it was impossible to say for certain, there were likely just a few weeks left." Knowing that, the patient decided to fly back to

China to see his daughter and family and live his last days with those he cared for around him. "Afterwards, the daughter called to thank me for being so truthful, because it meant they were able to make the decision to be together in those final days," said Savi.

Serving in the diverse New York City community, members of the VNS Health Hospice Care team care for families of many backgrounds, that are sometimes very different from their own. Whether bonding over shared experiences or getting to know patients from cultures that are radically different from their own, building these one-on-one connections are among the most rewarding aspects of being a home health care clinician. For Savi and Ling, building those bonds as a life nears its end is more than a job—it's a profound and meaningful honor.

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