

Alzheimer's presents unique cultural challenges for Chinese families

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If dementia were a country, its economy would rank 18th between Turkey and Indonesia. The total estimated global cost of dementia in 2010 is slated to be \$604 billion, according to Alzheimer's Disease International. The sharpest increase in the 35.6 million people across the world with dementia is now occurring in rapidly developing regions -- especially in China.

Yu-Ping Chang, University at Buffalo assistant professor of nursing, has published a study in *Perspectives in Psychiatric Care* on the unique challenges experienced by Chinese families in Taiwan when confronting Alzheimer's. She also has received a grant from the Alzheimer's Association to explore how Chinese immigrant families in San Francisco cope with Alzheimer's disease and how they use traditional Chinese herbal medicines to treat it.

Fundamental to Chang's research is the Chinese concept of filial piety or xiào. Xiào, which is inherited from the Confucian ideals, requires children from birth to death to be respectful of parents and ancestors.

Grown children practicing Chinese filial piety, Chang notes, are expected to reciprocate their parents' love for them with respect and gratitude. And when parents become ill, the children are to be solely and directly responsible for their care. Until recently, this did not include placing parents under the care of others.

For her study, "Decision-Making Processes of Nursing Home Placement



among Chinese Family Caregivers," Chang traveled to Taiwan to interview the caregivers of parents with Alzheimer's disease and found that the chief concern for them was the conflict between the need to place a loved one in a nursing home and filial piety.

Caring for parents with Alzheimer's disease presents many of the same challenges to modern Chinese children as it does children in the U.S. Caregivers often experience each day as 36-hours. Even when one or more children can be at home with a parent, parents with dementia are often eventually too difficult to care for, placing the burden on the children to find institutional means of care.

Among the Chinese, however, not living up to the ideals of filial piety can result in feelings of deep shame and failure far beyond the guilt that Western caregivers experience when they have to make the decision to place a parent in a nursing home.

While past research has shown that filial piety is a factor affecting nursing home admission, Chang's research in Taiwan identified four specific stages for Chinese when considering nursing home placement for a parent or elder.

- Initiating the placement decision -- prompted by deteriorating dementia behaviors
- Assessing and weighing the decision -- information gathering and involvement of the entire family
- Finalizing the decision -- family consensus was essential
- Evaluating the decision -- reconciling tense family relationships, examining quality of care



Though the demands of filial piety weighed heavily on caregivers during each phase, Chang found that they could compensate for it by finding the best nursing home, gaining the consensus of the entire family about placement (even aunts and uncles), visiting the nursing home frequently and checking in with the parent often for the quality of care.

For the two-year research project funded by the Alzheimer's Association in 2009, Chang is studying the relationship between Chinese immigrants' cultural beliefs and medication use in the San Francisco Bay area. Many Chinese immigrants self-medicate using traditional Chinese herbal medicine (TCHM), in addition to their regularly prescribed medications, without telling their physicians, Chang says. Or, perhaps, their Western physicians never asked them about use of TCHM due to a lack of awareness of the cultural issues.

As part of this study, Chang spent time with <u>Alzheimer's disease</u> sufferer Sir Charles K. Kao, 2009 Nobel Prize winner in physics (who is known as the father of broadband) and his wife, Gwen. Kao was diagnosed with Alzheimer's at about the same time he and his wife were notified about the Nobel Prize. Gwen Kao has become an advocate for Alzheimer's funding in California. According to Kao, the use of TCHM is common in this population, and many Chinese Americans suffering with Alzheimer's feel shame and, thus, do not seek help from medical professionals.

Because of the complexity of such cultural and medical issues, Chang's research will target family caregivers. She notes that patients suffering from dementia are often poor historians and can't accurately describe their medication use. And many Chinese-American children caring for a parent may dutifully continue to give TCHM out of filial piety.

"I think Chinese-Americans have different perspectives regarding dementia, such as attributing it to normal aging, the yin-yang imbalance,



mental illness, fate and the sins of their ancestors," Chang explains.
"These may potentially influence the way they take care of their loved ones. Thus, I want to understand if Chinese-American family caregivers use TCHM to treat dementia-related symptoms and how their cultural beliefs and other factors influence their medication."

The study aims to determine the scope of TCHM use, the common ingredients selected and the patterns of patient-clinician communication regarding TCHM use. Eventually, Chang wants to design culturally appropriate interventions for Chinese American family caregivers to better manage their caregiving task as well as maintain their own health.

Chang hopes her research instructs health care providers that Chinese families -- the patients and the caregiver -- may be at risk because of the cultural stressors involved in making this decision. She is especially concerned for Chinese immigrant families in the U.S. that are culturally isolated.

For example, in San Francisco, Chang points out, there are nursing homes that have large populations of Taiwanese, Mandarin and Cantonese immigrants where patients and their families have others who speak their language and understand their culture. But in many parts of the world, Chinese residents in <u>nursing homes</u> are alone.

"Chinese endure things often without complaint so they will not communicate distress," Chang says. "Nurses need to be aware of this and other cultural differences so that they can work more effectively with patients and families."

Provided by University at Buffalo

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