



# A Multi-level Approach to Reducing Racial and Ethnic Disparities in End-of-Life and Palliative Care in the Chinese-American Community

Main Author: Sandy Chen Stokes, RN, MSN, Chinese American Coalition for Compassionate Care  
Co Authors: Kimlin Ashing-Giwa, Ph.D., Dawn Gross, M.D., Ph.D., Nancy Clifton-Hawkins, M.P.H., M.C.H.E.S., Sophia Yeung, City of Hope



## ABOUT CACCC

The Chinese American Coalition for Compassionate Care (CACCC), the only coalition in the nation devoted to end-of-life (EOL) concerns in the Chinese community, is an active working coalition of over 1,300 individual members.

### Mission

- ♥ Improve advance care planning for Chinese by encouraging open dialogue about EOL issues
- ♥ Encourage provider partnerships in which expertise and resources are shared
- ♥ Develop EOL materials in English and Chinese
- ♥ Provide training for Chinese volunteers, caregivers and Health professionals
- ♥ Provide community outreach

## BACKGROUND

There are disparities in access to care, receipt of care, and quality of care when Chinese-Americans are compared with the general population, leading to fragmented care, inadequate or inappropriate symptom management, miscommunication with the patient and family, and a difficult death for the patient. Chinese Americans are also woefully underrepresented in medical research. These problems are especially apparent in the San Gabriel Valley, which has the largest concentration of Chinese-American communities in the United States.



## PURPOSE

Using interventions at the patient, family, community, health professional and health service levels, CACCC provided education and culturally appropriate resources about EOL issues for the Chinese American community and the healthcare providers who serve them.



## METHODS

### Health Professional Workshops

To improve communication and cross cultural understanding between health care professionals and Chinese patients and their families about EOL care.

- ♥ Disseminate culturally and linguistically appropriate Palliative care and EOL materials
- ♥ Heart to Heart Café Facilitator Training
- ♥ Panel Discussions: Real Life Experiences in EOL



### Community outreach & Heart to Heart™ Cafés

Established the CACCC Speakers Bureau to provide education outreach to Chinese Americans on Advance Care Planning, including AHCD, POLST, and EOL Care.

**Heart to Heart™ Cafés:** A group of participants gather to discuss EOL issues, using the CACCC's Heart to Heart™ cards to facilitate EOL discussion. The cards contain both English and Chinese.



### 2011 & 2014 EOL Volunteer training

Developed and conducted Chinese EOL Volunteer Training for bilingual Chinese volunteers who serve in hospices and hospitals to provide culture and language appropriate support for Chinese speaking patients & families.

## RESULTS/FINDINGS

Three 2014 Health Professional Workshops: Methodist Hospital, HealthCare Partners, City of Hope, San Gabriel Valley End of Life Care Coalition (SGVEOLCC) & California Asian American Nurses Association. 250 participants from over 40 agencies attended the workshops in 2014. Responses to "What I learned is highly relevant to my job", 87% strongly Agree, 13% Agree. 94% in 2011, 99% in 2014 rated the training excellent or good.

CACCC provided 6 community outreach presentations and 17 two-hour Heart to Heart™ Cafés in 12 cities to initiate end of life conversation among 100 Chinese Americans.

### Top 5 most preferred cards

	%	Heart to Heart Message
3 Spades	9.4	I don't want to be kept alive by machines.
A Clubs	8.3	I don't want to be a burden to my family
A Hearts	6.7	I want to maintain my dignity
Q Hearts	6.6	I want to die without regret
A Spades	5.6	I don't want to suffer

### Suit Preference According to Place of birth



70 Chinese Hospice & Palliative Care Volunteers completed 30-hour trainings in 2011 (City of Hope) & 2014 (Methodist Hospital). These trained volunteers are being matched with hospice and palliative care agencies and Methodist Hospital, who partnered with the CACCC on this project. Some have already begun to serve Chinese patients.

## DISCUSSION/CONCLUSION

- ♥ Education of health professionals and the public is essential to moving towards a health care system that provides quality EOL counseling and palliative care to patients and families.
- ♥ Early Advance Care Planning discussions using culturally and linguistically appropriate materials are associated with less aggressive care and greater use of hospice and palliative care.
- ♥ Heart to Heart™ Cafés provide a safe and comfortable environment for discussing EOL concerns.
- ♥ Heart to Heart™ Cafés need to expand their services to include a large number of older Chinese who are born outside of Taiwan.
- ♥ Future research and funding should be directed toward interventions that address the specific needs of the Chinese-American population.

## CITATIONS

1. Chinese American Coalition for Compassionate Care "Learning to Let Go: Saying Goodbye Peacefully" (2013)
2. Chou, W. Y., Stokes, S., et al. "Improving End-of-Life Care Through Community-Based Grassroots Collaboration: Development of the Chinese-American Coalition for Compassionate Care" (2007)
3. National Hospice & Palliative Care Organization Caring Connections "Chinese-American Outreach Guide" (2007)
4. Edrington, Janet, et al. "Barriers to pain management in a community sample of Chinese American patients with cancer." (2009)
5. Hospice Foundation of America "Doing Everything We Can" (2009)
6. Hospice Foundation of America & Chinese American Coalition for Compassionate Care "Loving Life, Understanding Hospice" DVD, Sponsored by the Centers for Medicare & Medicaid Services (2009)
7. Hsiung, Yi-fang Yvonne, and Carol Estwing Ferrans "Recognizing Chinese Americans' cultural needs in making end-of-life treatment decisions" (2007)
8. Johnson KS, Racial and Ethnic Disparities in Palliative Care (2013)
9. Liu, Cathy Yang, Jonathan Miller, and Qingfang Wang "Ethnic Enterprises and Community Development" (2014)
10. Ngai-Metager Q, Phillips RS, McCarthy EP. "Ethnic Disparities in Hospice Use Among Asian-American and Pacific Islander Patients Dying with Cancer(2008)
11. Sheba George, Nelida Duran, and Keith Nantia. A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders (2014)

## FUNDING

California HealthCare Foundation, HealthCare Partners, Methodist Hospital & Coalition for Compassionate Care of California (CCCC)  
Other Event Sponsors: City of Hope, All Care Hospice, VITAS Innovative Hospice, Roze Room Hospice, Mission Hospice, Nurses Plus Hospice, Sanctuary Hospice, Seasons Hospice, Companion Hospice