

Improving End-of-Life Care Through Community-Based Grassroots Collaboration: Development of the Chinese-American Coalition for Compassionate Care

WEN-YING SYLVIA CHOU, Cancer Prevention Fellowship Program, Office of Preventive Oncology, National Cancer Institute, National Institutes of Health, Bethesda, Maryland, SANDY CHEN STOKES, El Dorado County Public Health Department, Placerville, California, JUDY CITKO, California Coalition for Compassionate Care, Sacramento, California, BETTY DAVIES, Department of Family Health Care Nursing, University of California San Francisco, San Francisco, California, USA

Abstract / As a volunteer-formed, community-based organization devoted to improving the quality of end-of-life care for Chinese Americans, the new Chinese-American Coalition for Compassionate Care (CACCC) is a unique and promising venture. This article has several aims: 1) to describe the history and development of the recently founded CACCC; 2) to introduce and critically evaluate one of CACCC's first public programs, a volunteer and caregiver training on end-of-life care, which prompted subsequent programs and activities; 3) to report on CACCC's current projects and short- and long-term goals; and 4) to discuss the implications for other similar community-based organizations devoted to the health and quality of life of a targeted population.

Résumé / Une nouvelle association vouée à l'amélioration de la qualité des soins en fin de vie chez les Américains d'origine chinoise est une avenue unique en son genre et très prometteuse. Connue sous le nom de *Chinese-American Coalition for Compassionate Care* (CACCC), cette organisation basée dans la communauté chinoise est composée de bénévoles. Cet article a pour objectifs : 1) de décrire l'historique et le processus de développement de la CACCC ; 2) de faire connaître et évaluer le programme initial de formation, ce cours sur les soins de fin de vie destinés aux bénévoles et aux soignants ayant donné naissance à d'autres programmes et activités de même nature ; 3) de présenter les projets courants de la CACCC, tout comme ses buts et objectifs à court et à long terme ; 4) de parler des conséquences de l'implantation de tels programmes par des associations communautaires s'adressant à une population cible et de faire des mises en garde.

INTRODUCTION

With the minority¹ population of the US expected to reach 50% of the total population by 2050,

¹In using the word "minority", we follow the definition of the U.S. Census as someone who is not a non-Hispanic white.

health care settings are becoming increasingly diverse (U.S. Bureau of the Census) (1). Compelling evidence suggests that race and ethnicity correlate persistently with health disparities in the US. Minority patients and family caregivers face extra burdens as they navigate the US healthcare system. A major goal of public health policy is to address the needs of the immigrant population. Various governmental efforts (e.g., Healthy People 2010 Initiative, the Office of Minority Health) are devoted to reducing and eliminating health disparities related to racial differences (2,3).

One can address the issue of health disparities in a number of ways, including cultural competency training of providers (4). Our focus will be on the role of community-based, culturally tailored, health promotion programs targeting minority patients and caregivers. It has been shown that the community plays an important role in health education (5) and, in particular, that minorities in one study showed greater enthusiasm for and a higher participation rate in health promotional programs tailored to their ethnic groups (6). The most systematic framework for community health promotion is community-based participatory research (CBPR), which involves community partnerships; it has demonstrated unique advantages and can serve as a useful guiding framework during the formative phase of community organizations (7,8).

Within the context of end of life (EOL), attitudes towards decision making, truth telling, and the use of life-prolonging technology vary greatly across ethnic and cultural groups

(9–11). Such culturally specific EOL attitudes and practices point to an urgent need for culturally tailored health care delivery and health promotion that educate minority patients and caregivers about important EOL issues. This need is compounded because most existing comprehensive EOL educational materials in the US are designed for the mainstream population, failing to attend to minority needs.²

In California, the need for culturally tailored education programs for patients and caregivers is especially great. This state is projected to receive the largest number of international migrants to the US in the next 30 years—more than one-third of all immigrants to be added to the nation's population over that period. Of all US States, California continues to have the largest share of the nation's Asians. By 2025, 41 percent of the Nation's 21 million Asians are expected to reside in California. Within the Asian immigrant population, Chinese Americans make up the largest subgroup (1).

With regard to attitudes towards EOL, a survey by the California Healthcare Foundation (2006) showed that Asians represent the ethnic group that has thought the least about and feels least comfortable talking about their EOL decisions (12). Asian's and Pacific Islander's use of hospice programs is also significantly lower (just 1.7% in 2004) than other ethnic groups in the US (14,15). Specifically, Chinese, as a subset of the Asian population, had the least knowledge of hospice (13).

To respond to Chinese Americans' needs for EOL information and care, a community-based organization was recently formed by a group of activists in northern California. The Chinese-American Coalition for Compassionate Care (CACCC) is a unique venture in several ways. First, the CACCC is the only organization in the U.S. that is solely devoted to EOL education and services for Chinese Americans, and one of few community-led efforts devoted to minority EOL needs. Second, its entire membership is made up of volunteers who share expertise in a wide range of health-related areas, such as nursing, social work, psychology, and community education. Third, one of its main missions is to promote cultural sensitivity regarding EOL care. It aims to heighten public awareness of the cultural and linguistic diversity in EOL care and education.

In this paper, we introduce the background, history, goals, and projects of the CACCC. We report on the coalition's first caregiver and volunteer training program, held in August 2006,

followed by a critical evaluation of this training. We then discuss the coalition's current projects and short-term plans. We believe the experiences of this new volunteer organization can serve as a guide for similar community-based health-related programs.

THE COALITION

Background

In past decades in the U.S., a number of community organizations have attempted to provide EOL education to Chinese-speaking immigrant communities. For example, the American Cancer Society's California Chinese Unit (ACS-CCU) and various faith-based groups have developed services educating the community about advance directives and EOL care options. However, individual organizations' efforts have not had a significant effect on the community as a whole. While the ACS-CCU has recently formed a volunteer respite program for cancer patients, its main focus is on providing direct and practical patient care, rather than on EOL education. Recently, faith-based groups such as the Herald Cancer Care Network and Tzu Chi Foundation have become instrumental in providing culturally sensitive care and information to Chinese Americans. However, they tend to be narrow in scope as a result of their religious base. Moreover, none of the organizations have a primary focus on EOL care, and most hospice and palliative care programs lack staff and volunteers familiar with the needs of Chinese-speaking patients.

In light of the particular needs of Chinese-speaking patients and the lack of comprehensive available EOL information, one of the authors (SCS)—a public health nurse, activist, and executive director of the CACCC—conducted a series of needs assessments to identify the challenges facing Chinese Americans. The assessment included focus group discussions conducted in Mandarin and Cantonese with 82 Chinese Americans, and interviews with eight Chinese-speaking physicians in the San Francisco Bay Area, the Greater Sacramento Area, and Southern California. The results confirmed a lack of linguistically and culturally appropriate EOL information for Chinese Americans. Specifically, the majority of those interviewed reported not having adequate information for making informed choices about EOL medical care, and many who had experienced the death of a family member reported that they would have made different decisions if they had had more

² Searches on the Web site of the National Hospice and Palliative Care Organization showed that, except for a small "Q&A" section in Spanish, all available resources and materials are targeted at an English-speaking mainstream population.

complete information at the time. Furthermore, most felt their choices were limited to only two options: aggressive life-sustaining measures or "giving up". This feeling is generally fostered by the following: first, there is a lack of information in Chinese on pain management, hospice care, the dying process, and advance health care directives; second, there is poor communication between patients and providers due to linguistic and cultural differences—the provider's poor cultural competence often results in a lack of trust; finally, there is generally a deep fear of addiction to pain medications, even in the last stage of illness. In addition, as noted by several Chinese-speaking physicians, a strong taboo exists within Chinese culture against talking about death and dying. The taboo includes the beliefs that talking about death will result in an earlier death, and that dying at home will bring a bad spirit to the people living in the house and to the house itself (which affects its value and marketability). This needs assessment confirmed existing research findings on attitudes towards EOL among Chinese-Americans (9–10,16). Given that these identified problems could not be easily addressed by available palliative care or hospice programs, nor within existing Chinese-American community organizations, the needs assessment prompted the founding of the CACCC.

Goals and Initial Development

A group of Chinese-American community activists, under the leadership of Ms. Stokes, formed an exploratory group in December of 2005 to establish the CACCC. This original group included individuals with diverse professional backgrounds: physicians, social workers, nurses,

hospice volunteers, representatives of various religious communities, and those with extensive patient care experience. The group developed the CACCC mission and vision statements (Figure 1).

The coalition's primary goal is to provide information, education, resources, and tools to:

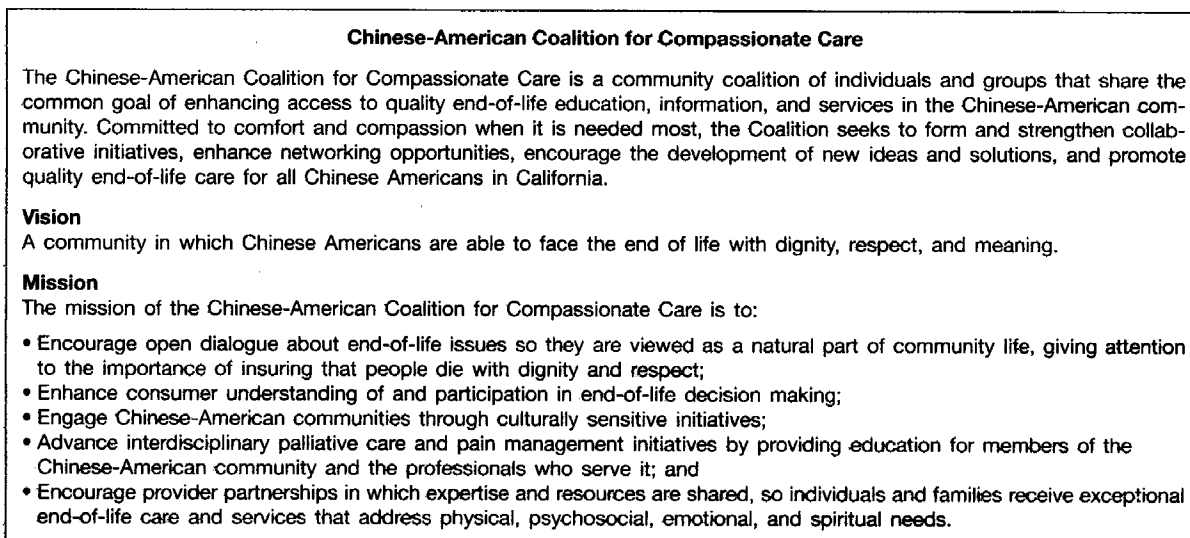
- Chinese Americans, including patients, their loved ones, and volunteer caregivers;
- health care providers who care for Chinese-American patients, and
- the general Chinese-speaking public.

The coalition aims to consolidate the most relevant and reliable information on EOL to ensure a centralized information source for Chinese-American communities. Currently, CACCC's efforts are focused on the greater San Francisco Bay Area, as the size of the Chinese-American population makes it an ideal location for testing the coalition's services and programs at this initial stage. With time, the Coalition plans to expand its services throughout California and nationally.

The coalition identified two projects for the beginning phase of the organization: 1) to provide EOL care training for volunteers and caregivers; and 2) to create an enhanced resource database for the Chinese-speaking population. Both projects have been implemented and will be reviewed in the following sections.

In order to minimize the initial costs associated with establishing a new organization, the CACCC received operational support from the California Coalition for Compassionate Care (CCCC) based in Sacramento. CCCC is a statewide collaborative of more than 60 organizations

Figure 1 / CACCC VISION AND MISSION STATEMENT



devoted to improving EOL care for Californians. One of its main aims is facilitating the development of programs for local ethnic minority communities. While the CCCC continues to provide operational support, CACCC is formally incorporated and has been approved as a tax-exempt 501(c)(3) nonprofit public organization.

To date, the CACCC has grown to over 160 members from more than 45 health-related organizations. Individuals come from a variety of professional backgrounds, including physicians, nurses, psychologists, social workers, attorneys, religious leaders, and community program coordinators, while others come from areas not directly related to health care, such as the technology industry and law.

PILOT TRAINING

Training Overview

The daylong pilot training for current or potential volunteers and caregivers was held in August 2006. This pilot training was intended to inform future educational events and curriculum development, so multiple methods were used to evaluate the project's strengths and weaknesses. The training also allowed for the creation of an EOL training curriculum in Chinese that may be adapted by other organizations.

Ninety-nine participants attended the training, one-third of whom were already involved as volunteers with the American Cancer Society California Chinese Unit. The majority were Chinese (n=93) and female (n=81), and ranged in age from 30 years to 65 years. Volunteer presenters included oncology nurses, a public health administrator, a psychologist, and a linguist, ensuring an interdisciplinary approach to EOL. In addition, community leaders from local Catholic, Protestant, and Buddhist communities introduced EOL attitudes and practices of their faith traditions during the module on spiritual needs. The workshop was conducted in Mandarin Chinese, with simultaneous translation to English-speaking attendees.

The curriculum was based on current research and educational materials, and the following topics were deemed most important: hospice programs, advanced directives, symptoms and pain management, communication problems and potential strategies, and cultural and spiritual beliefs associated with death and dying. These topics were incorporated into four 90-minute modules: 1) introduction to EOL; 2) EOL spiritual issues; 3) guide to caring for seriously ill patients; 4) psychosocial issues at the EOL (Figure 2).

Figure 2 / OUTLINE OF CACCC PILOT CURRICULUM

Module	Major Topics Covered
1. Introduction to EOL	<ul style="list-style-type: none"> • Overview of EOL issues in the US • Hospice and palliative care • Advance directives • Importance of skilled communication in medical setting and in the family
2. EOL spiritual issues	<ul style="list-style-type: none"> • Common spiritual needs at the EOL • Techniques for addressing patients' and families' spiritual needs • Major religious views and practices regarding death and dying (Buddhism, Protestantism, Catholicism, Islam)
3. Guide to patient care	<ul style="list-style-type: none"> • Common symptoms at the EOL • Pain management • Process of dying • Verbal and nonverbal communication with patients and families
4. EOL psychosocial issues	<ul style="list-style-type: none"> • Mental health problems at the EOL • Cognitive and interpersonal issues • Understanding EOL decision making

Attendees received a binder containing bilingual PowerPoint slides; a list of community resources, including those specifically tailored to Chinese Americans; and reference materials.

Assessment of Training

The three-part assessment of this training included: 1) a written evaluation completed by participants immediately following the training (Appendix A); a follow-up questionnaire in both English and Chinese mailed to all participants four months post-training (Appendix B, the English version); and telephone interviews with the coordinators of sponsoring organizations to seek feedback on the effect of the pilot training on their programs.

The response rate for post-training evaluation was 81%. The majority of respondents (74%) rated the overall workshop "most helpful" or "very helpful". Choice of topics, event organization, the training facility, chiropractor-led exercise breaks, interpretation service, resource table, and printed materials all received high marks. In Table 1, feedback on the modules is summarized for two key questions.

Modules 1 and 3 were highly rated as meeting the objectives and providing valuable information; Module 4 received less favourable results. Written comments indicated a possible reason for the difference: participants preferred the personal patient care experiences reported by the nurse speakers, and the practical nature of the discussion on communication and techniques for comfort care. When asked about the most valuable parts of the training, most participants mentioned role-playing exercises, presenters' sharing of personal experiences,

