

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

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**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 minority<sup>1</sup> population of the US expected to reach 50% of the total population by 2050,

<sup>1</sup>In 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.<sup>2</sup>

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

<sup>2</sup> 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:

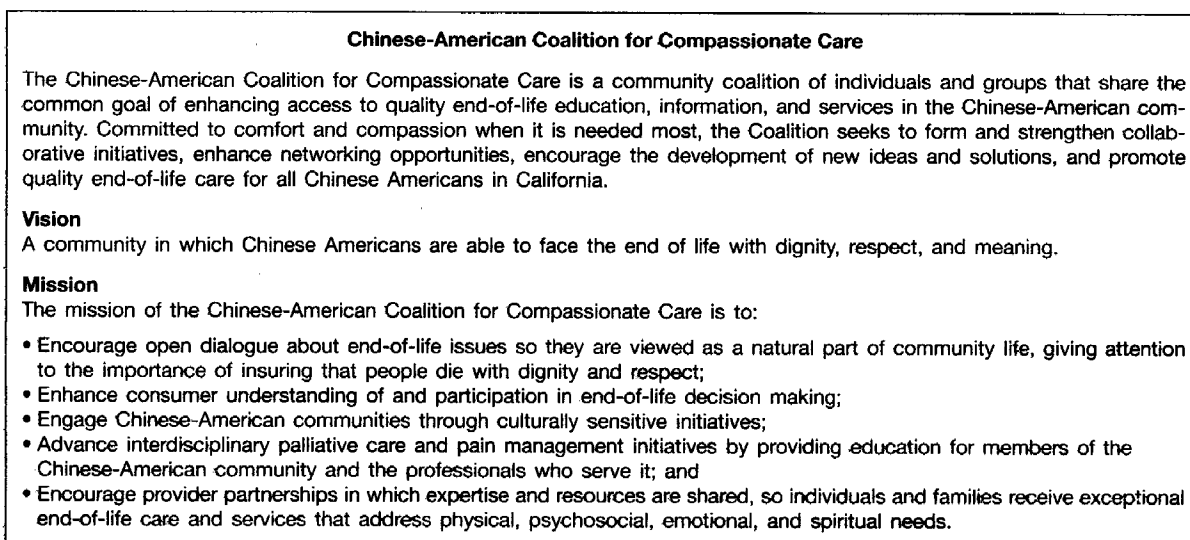
- Chinese Americans, including patients, their loved ones, and volunteer caregivers;
- health care providers who care for Chinese-American patients, and
- the general Chinese-speaking public.

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

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,

**Table 1 / SUMMARY OF MODULE EVALUATIONS**

How well did the presentation in this module meet its objectives?						
Module	Number Responding					unanswered
	(1) poor	(2) fair	(3) satisfactory	(4) good	(5) excellent	
1	0	0	10	37	28	5
2	0	5	14	29	23	9
3	0	1	14	27	31	7
4	1	17	18	27	10	7

**I gained valuable information from this presentation**

Module	Number Responding					unanswered
	(1) strongly disagree	(2) disagree	(3) neutral	(4) agree	(5) strongly agree	
1	0	1	3	21	47	8
2	0	2	7	31	30	10
3	0	1	4	25	33	17
4	1	5	15	30	22	7

the presentation on language and communication, the introduction to spiritual issues, and the discussion of cultural diversity. Interactive formats were generally preferred, and concise presentation of practical educational materials were desired, reflecting the participants' perceived needs, since volunteer trainees typically had little patient care experience.

A second evaluation was conducted four months after the training; participant responses are summarized in Table 2. Participants said the training made them aware of the complexity of issues surrounding EOL care, and emphasized the importance of respecting patient choices and autonomy, active listening, appreciating the need for more openness to talking about death and dying, and finally, understanding cultural diversity with regard to EOL attitudes. The single most commonly mentioned theme for suggestion on improvement was the need for more hands-on, practical materials, including role playing, case studies, and interactive discussions. This feedback was consistent with comments gathered immediately after the training.

Concurrent with the distribution of follow-up questionnaires, one author (SCS) elicited reactions to the training from the representatives of the ACS-CCU and the Herald Cancer Care Network (HCCN) regarding the training from the organizations' perspective.<sup>3</sup> Agency coordinators reported that their staff and volunteers gave overall positive feedback on the training. They suggested that future training spend more time on issues of financial and legal planning, making funeral arrangements, and initiating EOL conversations with family members. Consistent with the individual evaluation results, the organization representatives also reported the potential usefulness of having more interactive learning.

**Table 2 / RESPONSES FROM THE FOLLOW-UP QUESTIONNAIRE**

Background of participants	nurse (2) volunteer (24) social worker (2) caregiver (1) other (2) – pharmacist
Patient-care time	0 hours a week (18) 1–10 hours a week (6) 11–20 hours a week (2) 21–30 hours a week (1) 31–40 hours a week (4) 40+ hours a week (0)
Currently caring for EOL patients?	yes (7) no (24)
Relationship to patient cared for	self (1) nurse (2) volunteer (3) daughter (1)
How useful has the training been in your work?	not at all useful (1) somewhat useful (12) moderately useful (8) very useful (6) not relevant (4)
How useful has the training been in your thinking about EOL issues?	not at all useful (0) somewhat useful (8) moderately useful (7) very useful (16)

### Lessons Learned, Tangible Outcomes

**Content and Mode of Training.** Many respondents preferred more hands-on information, such as patient communication strategies and nursing care tips. While we recognize this, we also see the importance of providing certain types of information, such as general legal and ethical issues in EOL, and the importance of protecting patient confidentiality, as a part of any health care volunteer training. One way to make such "less practical" content more accessible is to improve on the presentation method

<sup>3</sup>ACS-CCU and HCCN were the largest groups that sent volunteers and staff to the training, with 38 volunteers and staff members from ACS-NCCU and six from HCCN.

by including role-playing exercises, group discussions, and case presentations. Specifically, the coalition is considering offering workshops focused on a particular module or on one specific topic such as symptom management, EOL decision making and advance directives, or volunteer-patient dynamics and communication.

**Evaluation.** The evaluations were originally designed with the goal of providing informal descriptive feedback for the curriculum committee only. As a result, the responses lacked statistical power. With financial support, future training will aim for a more comprehensive assessment to obtain a better understanding of the efficacy of this type of training. Moreover, many participants did not answer all of the questions (as indicated in the "unanswered" category in Table 1). The low completion rate may be remedied by an explicit reminder at the distribution of the questionnaires, creating a separate "no opinion" response, and offering more incentives for completion.

**Tangible Benefits.** This training resulted in two tangible benefits. First, it produced a large volume of bilingual written materials and a comprehensive resource list, with detailed information on patient care, communication, and spiritual and psychosocial issues. These EOL materials have been approved and adapted by the National Hospice and Palliative Care Organization for inclusion in their archive of bilingual materials. The materials have also been posted for the general public on the CACCC Web site ([www.caccc-usa.org](http://www.caccc-usa.org)). A second valuable outcome is that many of the training participants have taken steps to become volunteers. The ACS-CCU began its respite care volunteer program one month after the coalition's training, and 28 of its 45 current respite volunteers attended the pilot training. In addition, a number of participants have signed up for further training to become formal hospice volunteers. Finally, this training has garnered wide publicity in the local Chinese media and attracted the attention of funding agencies, such as the Lance Armstrong Foundation and the Stanford Geriatric Education Center, partially contributing to CACCC's subsequent successes in securing organizational grants.

## COALITION'S CURRENT PROJECTS

### Lance Armstrong Foundation Grants

In addition to the caregiver training, receipt of a number of grants has enabled the CACCC to launch a number of projects. A one-year grant

from the Lance Armstrong Foundation (LAF) had three components: conducting a media campaign, developing a speakers' bureau, and disseminating written materials about EOL to Chinese cancer survivors in the greater San Francisco Bay Area. Through the media campaign, the CACCC has establishing partnerships with three San Francisco Bay Area Chinese-language newspapers, a radio station, and a television station to produce articles and programs on palliative and EOL care targeted to Chinese-speaking cancer survivors. The speakers' bureau has trained 15 experienced health care professional volunteers to give culturally appropriate presentations on EOL issues to Chinese-speaking communities, including advance care planning, hospice and palliative care, pain management, advanced health care directive, and EOL quality-of-life issues. In the process, curriculum and informational materials have been developed (with the translation into Chinese of a number of English educational materials, such as a glossary of EOL terminology, the advanced health care directive, and fact sheets) and disseminated to various organizations and healthcare facilities. As of June 2007, CACCC has offered a total of ten presentations to more than 400 audience members. Finally, also as a part of the LAF grant, CACCC has recruited community organizations to disseminate an EOL educational booklet created by the CCCC (*Medical Decisions Near the End of Life: Mrs. Lee's Story*), produced by Sacramento Healthcare Decisions (17). All of the 2,000 booklets printed have been distributed through 12 community organizations, clinics, churches, and temples.

Upon successfully completing all the projects funded by the first grant, CACCC has received a second grant from LAF. This grant is devoted entirely to providing psychosocial and emotional support for EOL caregivers and volunteers. Aiming to directly benefit 100 individuals, the Coalition plans to build a curriculum specifically on the caregivers' psychosocial needs (in consultation with the San Francisco Zen Hospice Project), and to promote it with lectures and workshops throughout the greater San Francisco Bay Area, in association with the America Cancer Society California Chinese Unit and the Herald Cancer Network.

### Continued Training and Public Education Activities

CACCC has recently received an additional three-year grant from Stanford Geriatric Education Center. The aims of this grant are to provide trainings for health professionals in working

with the Chinese-speaking population, and to provide trainings for medical interpreters and volunteers on the special needs of Chinese-speaking patients and caregivers. The trainings, targeted at approximately 60 physicians, nurses, and social workers (recruited through local healthcare facilities, medical schools, and hospice programs) who frequently work with Chinese-speaking patients, will consist of two half-day seminars. Issues covered will include linguistically and culturally tailored communication strategies; advanced care planning discussion; cultural, spiritual, and medical issues specific to Chinese patients (including the use of complementary alternative medicine in combination with Western medical options); and common beliefs about nutrition and hydration at the EOL. We believe that through this training, the CACCC will build partnerships and connections with San Francisco Bay Area health care professionals and professional organizations, not only informing them of our programs and providing services when needed, but also recruiting them to become actively involved with the goals and projects of the coalition.

In addition, to continue its education effort that began with the original pilot training discussed above, CACCC held a second volunteer and caregiver training, and a lecture for the general public, November 3-4, 2007. Founder and Medical Director of Taiwan's hospice organization Dr. Enoch Lai was invited to speak, along with an experienced hospice volunteer from Taiwan Ms. Grace Chang. The training included an overview of current palliative and EOL care in Taiwan, patient case reports, role-play exercises, and volunteer sharing. Sixty-six individuals attended the full-day training and 45 attended the lecture for the general public; participants provided strongly positive feedback.

#### **Nonprofit Organization Status and Board of Directors**

The CACCC's recent incorporation and tax-exempt status help ensure continued engagement of the Coalition membership, and allows the Coalition to receive grants and donations independently. The 15-member board of directors is made up of registered nurses, social workers, an attorney, religious leaders, doctors, and community activists. The board oversees curriculum development, fundraising events, media liaison, and Web site management.

#### **Coalition Web Site**

The CACCC Chinese-English bilingual Web site ([www.caccc-usa.org](http://www.caccc-usa.org)) has allowed the coalition

to reach a much wider audience than would otherwise be possible and, judging from the responses received from across the US, we are convinced that Internet media plays a key role in maintaining the visibility and sustainability of the Coalition. In addition to introducing the Coalition's vision and mission, educational materials, current resources, events, and meeting agendas are regularly posted and updated on the site. The Coalition is currently working to identify and contact established organizations and area hospices to provide links to the CACCC Web site. As of the February 20, 2008, the Web site had received more than 1,139,000 visits.

#### **Community and International Partnerships**

We believe that one of the most important ways to ensure sustainability is through meaningful partnerships with established organizations. The CACCC is extending its partnerships and connections with two types of organizations. The first is collaboration with mainstream US organizations with a focus on palliative and EOL care, where CACCC provides Chinese translations of exiting materials, and introduces to the leadership the Coalition's missions and programs. Currently, the National Hospice and Palliative Care Organization, the Children's Hospice and Palliative Care Coalition, and the California Kaiser Permanente Foundation are organizations that have actively sought collaboration with the CACCC. A second type of partnership involves collaboration with Chinese-speaking organizations, with whom resources and expertise can be shared. In particular, research has shown the importance of home country health beliefs, including EOL attitudes, decision making, and practices of the immigrant population (18). Materials that are sensitive to and tailored to the special needs of a population (e.g., Chinese Buddhists) are invaluable, but at the same time, difficult to collect without collaboration with the home countries. For example, the Tzu Chi Foundation has a renowned palliative care program in Taiwan, with EOL care resources incorporating Buddhist EOL beliefs. Their resources and experience are invaluable to Chinese-American patients, and health professionals and volunteers caring for Buddhist patients. Besides constant collaboration with ACS-CCU, the Tzu Chi Foundation, and the Herald Cancer Network, as described above, the CACCC has also established connections with palliative care organizations in Taiwan and, in the future, we hope to expand our partnerships to other EOL organizations throughout the Chinese-speaking world.

### Short-term Goals

In addition to the currently funded programs, the CACCC plans to extend and enhance the caregiver EOL training curriculum, developed from the pilot training and the speakers' bureau presentations, to eventually create a stand-alone curriculum on EOL care targeted at Chinese-speaking caregivers and volunteers that can be accessed by any organization or individual.

On the practical side, the coalition realizes that, with its rapidly expanding operation, it has become necessary to hire a paid staff member while continuing the strong volunteer involvement. Another goal, pending further funding, is to begin a toll-free information hotline to provide Chinese-speaking patients and caregivers with EOL information, support, and referral services throughout the US.

### Implications for Other Organizations

The early history of the CACCC may provide valuable guidance for others who wish to set up similar volunteer/community-based organizations. Several important lessons can be learned from the Coalition's first 22 months. First, strong leadership is key to initiating such an organization. The leader(s) need to be well connected in the community. In the case of the CACCC, Ms. Stokes had been an activist for quality EOL

care in the Chinese-American community of the Greater San Francisco Bay Area since 1999, thus, her name was well known and respected in the community. Her personal connections with organizations such as the ACS-CCU, the Tzu Chi Foundation, the Alzheimer's Association, the Diabetes Association, and other health professionals and activists were instrumental in bringing individuals with a variety of talents and skills into the project.

Second, for a grassroots organization to have any significant effect, a culture of volunteering must be in place within the community. Such a culture had already been established prior to the founding of CACCC. The majority of coalition members belonged either to ACS-CCU or to faith-based organizations in the Bay Area. Their prior experience with volunteering and collaboration was instrumental in getting the CACCC off the ground quickly.

Third, it is important to identify and carry out a well-defined, tangible project in the early phase of the organization to provide a feeling of shared purpose and accomplishment among members. The pilot training discussed above was a crucial event because it enabled volunteers from different backgrounds to work closely together. In other words, the two training programs not only benefited the attendees, but also solidified volunteer commitment to the Coalition.

**Table 3 / CACCC'S DEVELOPMENT AS COMPARED TO SUSTAINABILITY BENCHMARKS (FROM THE CENTER FOR COLLABORATIVE PLANNING)**

Benchmarks	CACCC's Key Developments	Comments and Potential Improvement
1. Has the organization "mobilized community residents who are committed to sustaining efforts to improve the community"?	<ul style="list-style-type: none"> <li>Identified and recruited highly skilled professionals experienced in EOL care and issues</li> <li>Has capacity to receive donations through its non-profit status</li> <li>Held media appreciation events to celebrate contributions</li> </ul>	Continue to create mechanisms to sustain the large membership through meaningful events and programs
2. Is the organization "sustaining its efforts through policy and systems change"?	<ul style="list-style-type: none"> <li>Mission statement specifies goals and allows systematic program evaluation</li> <li>Speakers' bureau provides opportunity for members to participate in relationship building and learning advocacy skills</li> </ul>	Although affecting public policy is not an immediate goal, policy on EOL could eventually be affected through raising community awareness
3. Is the organization "sustaining its efforts by spinning off or institutionalizing its effective strategies, activities, or programs"?	<ul style="list-style-type: none"> <li>Successful at finding collaborators in the Chinese-American community</li> <li>Located support through local institutions such as senior centres, faith-based organizations, and national organizations such as the NHPCO and Kaiser Permanente.</li> </ul>	May consider clarifying relationships with other organizations to delineate responsibilities and prioritize collaborative activities and programs.
4. Is CACCC "sustaining its efforts by successfully raising funds and/or proceeding with incorporation to sustain the core functioning of the collaboration"?	<ul style="list-style-type: none"> <li>Received multiple and continuous grants</li> <li>Officially incorporated as nonprofit organization under IRS 501(C)(3)</li> </ul>	May consider strategies to identify private donations and endowments
5. Has the organization "used evaluation findings to make revisions and does it function as a learning community"?	<ul style="list-style-type: none"> <li>Carried out informal evaluations of programs and trainings</li> <li>Relied on evaluation results to build improved programs and curriculum</li> </ul>	Continue to identify and implement "impact strategies"

Furthermore, one of the most important aspects of ensuring the Coalition's visibility and success is its media relations. At the onset, newspaper, radio, and television coverage of CACCC helped boost its name recognition within the Chinese-speaking community. The Coalition continues to maintain a close relationship with the Chinese-speaking media in the San Francisco Bay Area. In October 2007, a media appreciation luncheon was held to honour the journalists who support the Coalition.

Finally, at the same time the Coalition is rapidly expanding, its leadership strives to make sure the organization and its work are sustainable. One way to assess a grassroots organization's sustainability over a long period is to evaluate its development against a pre-existing, practical guide. To date, the most comprehensive guide to for community organizations is the benchmarks developed by the Center for Collaborative Planning, which contain a detailed worksheet concerning sustainability with specific questions concerning each of the five benchmarks (19, 20). Using the benchmarks as a guide, we have carefully considered CACCC's developments and potential areas for improvement. Table 3 summarizes the main points of the benchmarks and CACCC's developments in each area.

Although its history is brief, the Coalition has met all five of the benchmarks through its various partnerships, grants, and activities. In addition, the worksheet provides a practical mechanism for evaluating future directions of the Coalition; we have briefly discussed areas within each benchmark that could be targets for improvement and changes.

## CONCLUSION

In the last two decades, hospice and palliative care programs have significantly improved the quality of life for seriously ill patients in the US and many other countries around the world. With the increased presence and visibility of such programs, the public's awareness of EOL options has also increased. Nonetheless, significant gaps in the use of EOL resources exist across ethnic and cultural groups. The CACCC is a unique community-based organization that focuses exclusively on the needs of one ethnic group. Moreover, the CACCC is the first coalition that brings together clinical professionals (from hospitals and hospices), Chinese-American community organizations, researchers, and activists to work towards a shared goal of improving EOL quality of life for Chinese Americans. The Coalition also provides a forum for individuals to meet and exchange expertise

and experience, creating a social network and invaluable support system that would not otherwise exist.

In this report, we have discussed the Coalition's goals and projects, and critically assessed the pilot training for caregivers and volunteers. As a pilot program undertaken entirely by volunteers and with no organizational financial support, the training has provided a vehicle for improving future training and curriculum planning. As shown in the subsequent account of the Coalition's current activities and projects, it is apparent that the CACCC is on its way to achieving the long-term goal articulated in its vision statement: to improve the quality of EOL care for the Chinese-American community. Finally, the grassroots nature of this effort is unique and may provide a model for advocates of other ethnic or linguistic groups.

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