

Improving End-of-Life Care in Nursing Facilities: The Community State Partnership to Improve End-of-Life Care—California

TERRY E. HILL, M.D.,¹ MARJORIE GINSBURG, M.P.H.,² JUDY CITKO, J.D.,³
and MARY CADOGAN, Dr.P.H., R.N., C.G.N.P.⁴

ABSTRACT

Background: The California Coalition for Compassionate Care formed in 1998 when activists and organizational leaders in several arenas sought to link their efforts for synergistic impact on end-of-life care and to obtain funding to sustain their forward momentum and collaboration. The Coalition focused on public engagement, professional education, and reforms in skilled nursing facilities. With skilled nursing facilities, the Coalition's work built on the efforts of the ECHO (Extreme Care, Human Options) Long Term Care Task Force, which served as a precursor to the Coalition.

Objective: The Coalition's objective was to assist committed facilities in devising processes of care that would operationalize basic end-of-life care principles in a manner specific to their particular facility.

Design: The Coalition recruited three-member leadership teams from nursing facilities throughout California to attend a 2-day training program, write an action plan, and receive 6 months of modest follow-up support. To assess its success, the group used posttraining evaluations, a follow-up evaluation, a focus group, and informal feedback over several years to assess the dynamics, achievements, and challenges of their efforts.

Results: In 2000–2002 the training reached 298 people representing 109 nursing facilities and each district office of the nursing facility surveyors. Response to the training was enthusiastic. Self-reported improvements in 27 care practices were best in the areas of pain assessment and management. Completion of nursing facilities' self-identified action plans varied widely. Participants generally perceived the commitment to improving end-of-life care as a vehicle for improving the overall care and quality management in nursing facilities.

Conclusions: The specific challenges of organizational change in nursing facilities require sustained, focused leadership and hands-on guidance to overcome the inevitable barriers and setbacks. The Coalition's experience confirms that coalitions depend upon personal commitments and relationships, a focus on practical products, and a consistent infrastructure.

¹Lumetra, San Francisco, California.

²Sacramento Healthcare Decisions.

³California Healthcare Association.

⁴University of California, Los Angeles, California.

THE STATE PARTNERSHIP

THE CALIFORNIA COALITION FOR COMPASSIONATE CARE began to coalesce in May 1998 when leaders of several different initiatives met to explore a joint application for The Robert Wood Johnson Foundation's (RWJF) program, Community-State Partnerships to Improve End-of-Life Care (CSP). A sense of urgency and opportunity existed at that first meeting in Sacramento. The California Assembly had created a Select Committee on End-of-Life Care in late 1997 to examine issues related to palliative care and physician-assisted suicide. The Legislature was also considering legislation to reduce or eliminate the onerous triplicate prescription requirement for Schedule II opioid medications. There was a sense of familiarity at that meeting as well. Many of those gathered had worked together before on either the Sacramento-based ECHO (Extreme Care, Humane Options) project or on several state-wide projects to improve end-of-life care in nursing facilities.

The ECHO Project, begun in 1994 by Sacramento Healthcare Decisions, released *Community Recommendations for Appropriate, Humane Medical Care for Dying or Irreversibly Ill Patients* in January 1997.¹ These recommendations for acute facilities were produced for the Sacramento region based on findings from 92 community discussion groups, a telephone survey, and committees of health care professionals. Although regional in origin, more than 300 organizations throughout California soon requested copies of the recommendations. The California Public Employees Retirement System (CalPERS), the largest purchaser of health insurance in the state, endorsed the ECHO *Recommendations* and urged endorsement from health plans and state health care associations.

Meanwhile, an informal group of California nursing facility leaders and physicians had begun work in 1995 on shared medical decision-making in the nursing facility setting. In 1997 that work resulted in a revised "Physician Form for Documentation of Preferred Intensity of Treatment," published by the California Medical Association, triggering both local and statewide educational efforts. For the second phase of the ECHO project, in May 1997, Sacramento Healthcare Decisions invited nursing facility leaders, public officials, educators, and consumers to begin the statewide ECHO Long-Term Care Task Force. By

mid-1998 this group had drafted standards for achieving optimal end-of-life care in California nursing facilities.

The 1998 effort to form the California Coalition for Compassionate Care (The Coalition) emerged from these and other relationships. Given the size and diversity of California, the group knew it could not speak for all stakeholders, but it recognized the opportunity to create a formal network that would be able to attract others. Specifically, the Coalition sought to:

- Capture the momentum of efforts already underway;
- Connect these efforts to each other for synergistic impact;
- Attract the interest and commitment of new stakeholders, and
- Capitalize on this *critical mass* of involvement to build a foundation for sustained activity.

THE CALIFORNIA PARTNERSHIP— LEADERSHIP AND STRUCTURE

The Coalition took shape quickly, without substantial debate, and without any explicit differences in vision, strategy, or structure. The California Healthcare Association (CHA) agreed to house the Coalition and serve as its lead agency. Representatives of the initial 25 partnering organizations, primarily representing statewide constituencies, formed the Coalition's Steering Committee, a body committed to meeting 3–4 times a year to oversee the Coalition's activities. Workgroups formed to develop and carry out the Coalition's primary initiatives in public engagement, professional education, and nursing facilities. Each workgroup was given representation on the executive committee, which agreed to meet by conference call twice each month. In part, Coalition leaders recruited for the steering committee and workgroups the way they would for a board of directors, attending to stakeholder representation, influence, and diversity. Aware of the tasks ahead, however, they put greatest emphasis on recruiting enthusiastic and talented end-of-life content experts who would contribute to the Coalition's work products (Table 1).

Stipends were provided to workgroup chairs to help compensate for the considerable time and responsibility required of them. The CSP grant also covered a half-time administrative person.

TABLE 1. CALIFORNIA COMMUNITY-STATE PARTNERSHIP PARTNERS IN 2004^a

<p>Provider and professional associations</p> <p>Alliance of Catholic Health Care</p> <p><i>American Baptist Homes of the West</i></p> <p>Association of Jewish Family and Children's Services Agencies</p> <p>Beverly Health and Rehabilitation Services</p> <p><i>California Association for Adult Day Services</i></p> <p><i>California Association for Health Services at Home</i></p> <p><i>California Association of Health Facilities</i></p> <p><i>California Association of Homes and Services for the Aging</i></p> <p><i>California Association of Long-Term Care Medicine</i></p> <p>California Assisted Living Association</p> <p>California Funeral Directors Association</p> <p><i>California Healthcare Association</i></p> <p><i>California Hospice & Palliative Care Association</i></p> <p>California Institute for Health Systems Performance</p> <p><i>California Medical Association</i></p> <p>California Medical Training Center</p> <p><i>California Pharmacists Association</i></p> <p>California Society for Healthcare Attorneys</p> <p>California Thoracic Society</p> <p>Catholic Healthcare West—Sacramento Division</p> <p>Coalition of Nursing Organizations in California</p> <p>Jewish Family & Children's Services of the East Bay</p> <p><i>Lutheran Social Services of Northern California</i></p> <p>Mariner Health Care</p> <p>Mercy Healthcare Sacramento</p> <p>Northern California Kaiser Permanente</p> <p>QueensCare Health & Faith Partnership</p> <p>San Diego Hospice and Palliative Care</p> <p>Sutter Medical Group</p> <p><i>Visiting Nurses Association of the Inland Counties</i></p> <p>Governmental Agencies</p> <p>Assembly Committee on Aging</p> <p>Butte County Elder Services Task Force</p> <p><i>California Association of Area Agencies on Aging</i></p> <p><i>California Board of Registered Nursing</i></p> <p>California Department of Aging</p> <p><i>California Department of Health Services</i></p> <p>Office of the Attorney General</p>	<p>Educational organizations</p> <p><i>Stanford Geriatric Education Center</i></p> <p><i>UC Davis, West Coast Center for Palliative Care</i></p> <p>UCLA School of Nursing</p> <p>University of California, San Francisco</p> <p>Other organizations</p> <p><i>AARP—California</i></p> <p>ACCESS</p> <p>American Cancer Society, Northern California Chinese Unit</p> <p>California Council of the Alzheimer's Association</p> <p><i>California Council of Churches</i></p> <p>Children's Care Coalition</p> <p>Children's Care Coalition of Los Angeles</p> <p>Compassion in Dying Federation</p> <p>Growth House, Inc.</p> <p>National Senior Citizens Law Center</p> <p><i>Sacramento Healthcare Decisions</i></p> <p>Southern California Cancer Pain Initiative</p> <p>Community coalitions</p> <p>Butte County Elder Services Task Force</p> <p>Central Valley End-of-Life Coalition</p> <p>Claremont Coalition Concerned with End-of-Life Issues</p> <p>Coda Alliance</p> <p>Compassionate Care Alliance of Monterey County</p> <p>Compassionate Care Alliance of the Greater Sacramento Region</p> <p>Contra Costa Quality of Life Coalition</p> <p>East Bay End-of-Life Community Coalition</p> <p>End-of-Life Care Alliance of Sonoma County</p> <p>End-of-Life Care Coalition of Humboldt County</p> <p>End-of-Life Coalition of Monterey County</p> <p>Mendocino Coalition for Compassionate Care</p> <p>Nevada County Coalition for Compassionate Care</p> <p>San Fernando Valley End-of-Life Community Coalition</p> <p>San Francisco Bay Area Network for End-of-Life Care</p> <p>San Gabriel Valley End-of-Life Coalition</p> <p>Santa Clarita Valley End-of-Life Community Coalition</p> <p>Santa Cruz County End-of-Life Coalition</p>
---	---

^aFounding partners are shown in italics.

CHA contributed the part-time work of the Coalition executive director. Other partners contributed staff time to the partnership and, at times, paid for representatives to attend the steering committee meetings.

The group moved forward with the understanding that there was ample work to do within the common ground of the Coalition partners; there was no serious interest in exploring controversial boundary areas. Within this common ground, there was little interest in trying to pursue political activism together; moreover, such

activism would have been inconsistent with the requirements of CSP funding. The Coalition's public policy workgroup began and stayed small, playing an informational role.

The momentum of the public engagement initiative, similar to that of the nursing facility initiative, preceded the Coalition and continued unbroken, moving the Coalition forward with an established identity and credibility. Sacramento Healthcare Decisions, a small non-profit organization pivotal in forming the Coalition, had already developed community education tools,

such as the consumer booklet *Finding Your Way*,² and had established diverse ties in faith-based, senior, and health care settings. The Coalition was able to promote advance care planning activities statewide by recruiting additional partners in these arenas (e.g., the California Council of Churches, several health ministry networks, the state association of area agencies on aging, and AARP). In early 2000, when local coalitions around the state began working on an RWJF-funded initiative to promote the Public Television series *On Our Own Terms*, the public engagement workgroup reached out to these local groups and provided networking opportunities. These local groups ultimately became Coalition partners, allowing a synergistic relationship between local and statewide activities.

The professional education initiative began with good ideas but no collaborative precursor efforts and no coherent network of activists. An attempt to spur joint activity among California medical, nursing, and pharmacy schools did not gel, and the initiative experienced several changes in leadership and focus before eventually settling on two primary functions: introducing post-graduate end-of-life education programs into the state and developing consensus documents on advance care planning. Persistence among the Coalition's executive leadership and the commitment of several end-of-life activists eventually led to the initiative's stability and pivotal contributions.

The Coalition's efforts to recruit leadership from the major professional schools were initially unsuccessful. The exigencies of academic life only occasionally dovetail with collaborative efforts involving the community, other campuses, or even other schools on the same campus. Also, professional schools must prioritize graduate education over the much more distant challenge of improving care among practicing professionals in diverse non-academic settings. Nevertheless, in 2001 the Coalition was able to partner with several academic and hospice physicians to develop its hospital initiative under the Center to Advance Palliative Care program (www.capcmssm.org). This hospital-focused improvement project offered a more natural fit for academic clinicians and researchers, who are often hospital-based themselves. Hospitals also have the capacity to collect research-quality data that can advance the end-of-life care agenda and facilitate academic legitimacy.

THE NURSING FACILITY INITIATIVE

Project development and implementation

The Nursing Facility Workgroup accepted its charge from the ECHO Long-Term Care Task Force in the form of a consensus document about the tasks ahead. In February 1999 the *ECHO Nursing Facility Recommendations*³ were released in draft form for extended critique and field-testing. The broad-based approach taken by ECHO and continued by the Workgroup is reflected in Figure 1.

The *ECHO Nursing Facility Recommendations* emphasize the need for ongoing communication about the goals of care as residents' clinical situations change over time. Three workgroup members—a physician, a nurse, and an attorney from the state's licensing agency—developed a half-day curriculum on end-of-life decision-making based on the *ECHO Recommendations*. In April 1999 they piloted this curriculum in six diverse nursing facilities, which resulted in substantial revisions in the *ECHO Recommendations*, specifically in how advance care planning should be operationalized into routine care planning for all nursing facility residents.

There was consensus in both the ECHO Long-Term Care Task Force and the Coalition's Nursing Facility Workgroup that the latter provided a natural structure for continuing efforts to improve end-of-life care in nursing facilities. The ECHO Task Force had been composed of a diverse group of professionals and consumers, some representing organizations, others not. The Coalition's Nursing Facility Workgroup developed as a partnership among organizations. Half of the individuals in the ECHO Task Force became members of the Nursing Facility Workgroup, and the leadership of both groups was essentially identical. The ECHO Long-Term Care Task Force revised its recommendations for publication in the last months of 1999, and then disbanded. In January 2000 the Nursing Facility Workgroup published the *ECHO Recommendations*.

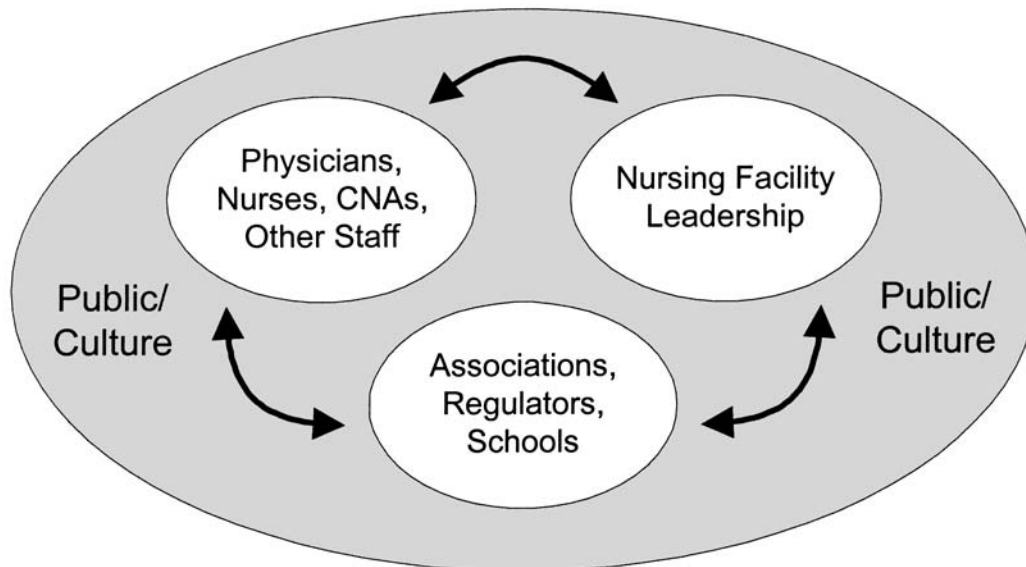
There also was consensus about the vital role of the licensing agency in improving nursing facility end-of-life care. The California Department of Health Services sent a copy of the *ECHO Recommendations* to every nursing facility and every nursing facility surveyor in California and paid to print and ship 100 copies of *Finding Your Way* to each of California's 1400 nursing facilities. Rep-

Changing What Happens in Nursing Facilities

Our challenge is to improve (1) end-of-life decision-making and (2) clinical aspects of palliative care in California nursing facilities. Meeting this challenge will require action in the following domains:

1. Healthcare professionals, non-licensed care providers, and public and private conservators
2. Corporate, administrative and clinical leadership of nursing facilities
3. Regulatory agencies, professional associations and academic institutions
4. The public and the prevailing culture of dying

The first three domains overlap and interact in multiple ways, all on a background of public and culture:



As a Coalition, we are supporting positive changes in each domain. This manual focuses particularly on actions in the nursing facility leadership domain and the healthcare professional domain. It is easy to see that changes in one can encourage changes in the other:

Nursing Facility Leadership

Administrative policies
Clinical policies, practices
Education
Monitoring
Resources availability



Healthcare Professionals

Knowledge
Attitudes
Skills
Behavior

Solitary interventions, such as rewriting administrative policy or even improving the knowledge of healthcare professionals, may have a short-term effect but are not likely to last. Conversely, a commitment to multiple interventions over time, with monitoring, can lead to new levels of expertise and a culture of compassion for the dying.

FIG. 1. A description of the broad-based approach to changing end-of-life care in nursing facilities that was adopted by the California ECHO taskforce and the coalition workgroup. Adapted from the *ECHO Nursing Facility Recommendations*.⁴

representatives from the licensing agency were leaders in the ECHO Long-Term Care Task Force, and the agency committed its support anew with each of the CSP grant applications. The ECHO Long-Term Care Task Force and the Coalition's Nursing Facility Workgroup consistently argued that there was no need for new state regulations targeting end-of-life care. The agency already had ample regulatory tools. On the provider side, with appropriate documentation facilities can defend individualized care focused on palliative goals. Perceived exceptions have generated serious review by workgroup leaders. These reform efforts have been based on the premises that (1) providers and surveyors need to develop shared understandings of good end-of-life care by working together on clear messages and joint trainings and (2) the commitment to improving end-of-life care is a vehicle for improving the overall care and the quality infrastructure in nursing facilities.

The Nursing Facility Workgroup's primary focus in late 1999 was expanding its end-of-life decision-making curriculum to encompass all aspects of end-of-life care and devising a rollout strategy (Fig. 2). The workgroup initially planned to offer ten 1-day regional trainings in 2000–2001, hoping to reach staff from a majority of the state's 1400 nursing facilities. Experts on the CSP's site visit team in 1999 expressed skepticism as to the efficacy of this educational strategy in changing practice. The workgroup quickly agreed—or “came to its senses,” in the words of one member—and adopted a smaller-scale, more intensive model.

The workgroup's pilot experience with its end-of-life decision-making curriculum in April 1999 suggested that its most effective contribution would not be teaching general principles of end-of-life care nor teaching specific processes that should be applicable in every setting. Rather, the workgroup decided to assist committed facilities in devising processes of care that would operationalize these principles in their particular settings.

The nursing facility training program, *Commitment to Compassionate Care*, called for a three-member leadership team from each participating facility to attend a 2-day training, write an action plan, and receive 6 months of modest follow-up support. Four hours of the 2-day training were devoted to assessing the facility's practice and developing an action plan using quality improvement principles. The curriculum included small-group exercises and case studies in addition to presentations. Participants received copies of the presentations and exercises for inservice use at their facilities, as well as various supporting materials produced by the Coalition's Public Engagement and Professional Education Workgroups (Table 2).

While nursing facility participants were engaged in the action-oriented portions of the curriculum (Table 3), surveyor participants engaged in a separate track discussing standards of end-of-life care and implications for regulatory oversight. The licensing agency attorney led these case-based discussions, focusing on whether the processes of care were appropriate rather than

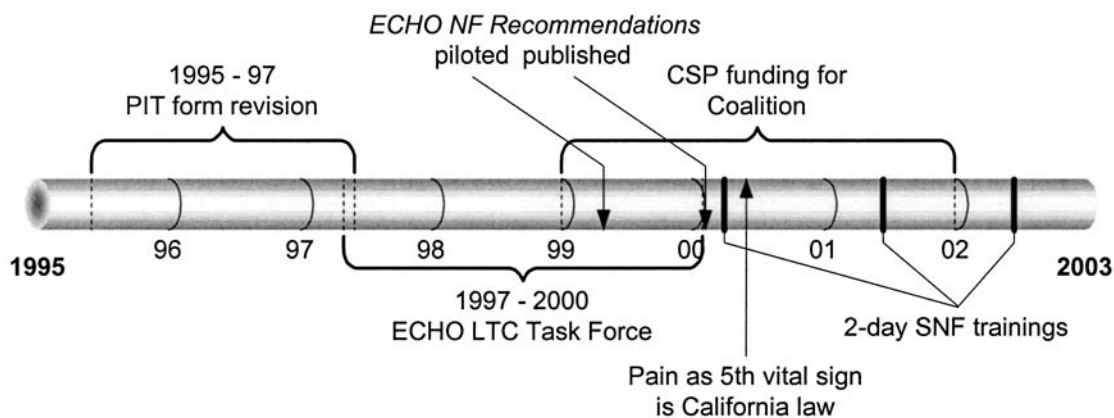


FIG. 2. Timeline for the Coalition's nursing facility initiative and precursors: Revision of the Physician Form for Documentation of Preferred Intensity of Treatment (PIT); ECHO Long-Term Care Task Force; ECHO Nursing Facility (NF) Recommendations; Community-State Partnerships funding for Coalition; and The annual 2-day nursing facility end-of-life trainings began in 2000.

TABLE 2. AGENDA OF TWO-DAY NURSING FACILITY TRAINING

<i>Min</i>	<i>Day one</i>	<i>Min</i>	<i>Day two</i>
15	Welcome and Introductions	45	Hospice/Nursing Facility Interface
25	What Is Good End-Of-Life Care?	60	Non-Pain Symptoms and Psychological Issues
15	End-Of-Life Decision-Making Survey		<i>Break</i>
25	Choices and Values Exercise	40	Nutrition and Hydration
	<i>Break</i>	40	Spirituality
70	Communication Skills		<i>Lunch</i>
30	Review of Survey Results	60	The Last 48 Hours
	<i>Lunch</i>	30	Brainstorming: Ideas, Barriers, and Solutions
90	Pain Assessment and Management		<i>Break</i>
	<i>Break</i>	70	Developing Action Plans in Small Groups
15	Assessment and Action Plan Strategy	20	Sharing Action Plans
70	Facility Assessment In Small Groups	10	Wrap-up and Next Steps
15	Wrap-up		

Exercises, tools, case studies, and slides are on coalition website (www.finalchoices.calhealth.org).

how to write deficiency reports. The trainings initially targeted leadership from regulatory district offices rather than field surveyors. The director of the licensing agency gave the training's opening "welcome" when she was available. The licensing agency attorney led some of the plenary sessions and was available for comment during the others.

The workgroup assumed, correctly, that nursing facility nurses would be the primary audience for the training and therefore targeted the level of instruction to this group. The few physician participants rated the trainings highly, and non-clinical participants, such as administrators and clergy, were able to glean useful information. The didactic portions of the curriculum were presented to physicians over 1999–2001 at annual seminars of the California Association of Long Term Care Medicine, a Coalition partner. In 2002 the workgroup developed a half-day curriculum on advanced topics for physicians in long-term care (palliative wound management, legal issues in advance care planning, the hospice/nursing facility interface, and organizational change) and presented it on two occasions. The California curriculum served as a model for the palliative care curriculum of the American Medical Directors Association, developed in 2002 under the direction of the workgroup's lead physician. Workgroup members also presented portions of the curriculum in multiple interdisciplinary settings and at other meetings of nurses, directors of nursing, physicians, surveyors, ombudsmen, and adult day health center staff.

In 2000–2002 this training reached 298 people representing 109 nursing facilities and each dis-

trict office of the nursing facility surveyors. The training evolved from year to year. In 2000 each facility was required to develop an action plan on pain in addition to an action plan on another topic. Pain became a fifth vital sign under California law in 2000, so in 2001 the workgroup relaxed the pain action plan requirement for facilities that had already made progress in this area. Based in part on evaluative feedback, in 2001 the workgroup developed an advanced track on cultural issues in end-of-life care. In 2002 the workgroup added a session on the hospice/nursing facility interface. The Coalition's Internet presence allowed the workgroup to post its curriculum publicly in 2000.⁵

In 2000 the workgroup offered multiple follow-up conference calls, then a half-day reunion after 6 months. The conference calls and reunions were modified in 2001 and abandoned in 2002, even though participants reported they were helpful. Workgroup members, almost all unpaid volunteers, struggled to participate in the calls and reunions. Workgroup members collaborated with the public engagement workgroup to bring together nursing facilities being trained and local community coalitions working to improve end-of-life care, sometimes with excellent results.

Participants rated the trainings highly and noted improvements in several areas of their facilities' practice. At the end of the 2-day training in 2000, 86% of respondents strongly agreed with the statement, "The program is likely to effect changes in the way I work." Of the 120 nursing facility staff who attended the 2-day training that year, 36% completed an evaluation 6 months later, representing 20 of the 43 facilities. In 2000,

TABLE 3. KEY STEPS OF THE ACTION-ORIENTED CURRICULAR STRATEGY

Day One Morning	
What is good end-of-life care?	
Have each participant write down one thing she hopes to gain from participating	
Describe examples of bad care, good care	
Describe the organizational change/action plan strategy	
Introduce "Changing practice in nursing facilities"	
Introduce "Assessing your facility" (which was mailed to participants)	
Day One Afternoon	
Assessment and action plan strategy	
Introduce "Checklist review after an expected death"	
Ask participants who have not completed the facility assessment to do so before tomorrow morning	
Introduce the action plan sheets ("Process improvement questions")	
Facility assessment in small groups	
Break into groups of 6–8 with participants from the same facility together	
Ask participants to identify themselves, their facilities, their roles, and what they hope to gain from conference	
Have participants complete "Checklist review after an expected death," using a recent death in their facility	
Have participants review and compare findings from "Checklist review after an expected death"	
Have participants review and compare findings from "Assessing your facility"	
Brainstorm barriers to improving end-of-life care in their facilities	
Brainstorm supports in their facilities, strategies to address the barriers	
Wrap-up	
Introduce Plan-Do-Check-Act cycle and "just-enough" data strategy	
Describe the next task: identifying action plan ideas, barriers, and strategies	
Mention the other synergistic activities of the Coalition and the Web site	
Day Two Afternoon	
Brainstorming: ideas, barriers, and solutions	
Have each participant write down, without consultation with others, two action plan ideas, two barriers, and two strategies to address the barriers	
Ask participants to volunteer to identify their action plan ideas, barriers, and strategies	
Have three different facilitators write down the ideas, barriers, and strategies on flip charts	
Developing action plans in small groups	
Reform the same groups of 6–8 with the same facilitator as on previous day	
Have participants from each facility (a team) work together to select a single action plan	
Have each team answer the "Process improvement questions" on NCR paper	
Ask teams to choose a representative to speak during the "sharing action plans" discussion	
Ask teams to discuss what support and communication would be helpful from the Coalition and from the other facilities over the next 6 months	
Sharing action plans	
Ask representatives from each team to describe their action plans	
Again mention the other synergistic activities of the Coalition and the Web site	
Describe the follow-up support available	

participating facilities created action plans regarding pain and one additional topic of their own choosing, often some aspect of advance care planning. As rated on the 6-month evaluations, the action plans on pain made the most progress overall (Table 4), and the most striking changes in practice were in that area (Table 5). Over 80% of respondents reported their facilities were "much better" or "better" in assessing and managing pain in cognitively intact residents and cognitively impaired residents. Less dramatic improvements were noted in documenting the goals of care, communicating with family members, family satisfaction, and overall attitudes about end-of-life care.

Respondents also rated the barriers to end-of-life improvements within their facilities (Table 6). Most prominent were inadequate knowledge and skills, inadequate staffing, staff turnover, and physician disregard for end-of-life issues. A Coalition-sponsored focus group in 2001 identified inadequate staffing, staff turnover, and inadequate administrative support as major barriers to improving end-of-life care in California nursing facilities. Workgroup members increasingly incorporated discussions of these barriers into the curriculum, encouraging facilities to create action plans that account for barriers and setbacks.

In 2003 and 2004 the workgroup modified the

TABLE 4. STAGES OF ACTION PLANS SIX MONTHS AFTER THE INITIAL YEAR 2000 TRAINING

	%					Mean	SD
	1 <i>Fully implemented</i>	2 <i>Early implementation</i>	3 <i>Final development</i>	4 <i>Early development</i>	5 <i>Initial planning</i>		
Pain action plan	37	20	5	24	15	3.39	1.6
Other action plan	21	24	5	21	29	2.87	1.6

Each facility was asked to prepare two action plans, one of which addressed a pain issue. The data reflect evaluations by 41 participants from 20 facilities, tabulated by individual participant rather than by facility. The means are derived by converting descriptors to ordinals where 5 = fully implemented, 1 = initial planning. SD = standard deviation.

TABLE 5. SELF-REPORTED PRACTICE CHANGES IN DECREASING ORDER OF MAGNITUDE

	%					Mean	SD
	1 <i>Much better</i>	2 <i>Better</i>	3 <i>Same</i>	4 <i>Worse</i>	5 <i>Much worse</i>		
1. Assessing pain in cognitively intact residents	39	46	15	0	0	4.24	0.7
2. Assessing pain in cognitively impaired residents	37	46	17	0	0	4.20	0.7
3. Managing pain in cognitively intact residents	24	66	7	2	0	4.12	0.6
4. Managing pain in cognitively impaired residents	22	66	10	2	0	4.07	0.6
5. Documenting the goals of care	26	43	31	0	0	3.95	0.8
6. Open communication with family throughout the dying process	22	51	27	0	0	3.95	0.7
7. Overall attitudes about end-of-life-care	20	53	28	0	0	3.93	0.7
8. Satisfaction of families/loved ones with end-of-life care	20	53	28	0	0	3.93	0.7
9. Assessing psychosocial needs	10	71	20	0	0	3.90	0.5
10. Involvement of all appropriate disciplines	22	46	32	0	0	3.90	0.7
11. Overall knowledge about end-of-life-care	15	61	24	0	0	3.90	0.6
12. Addressing psychosocial needs	13	64	23	0	0	3.90	0.6
13. Appropriate involvement of hospice	36	19	42	3	0	3.89	0.9
14. Awareness of residents and/or families regarding diagnosis and prognosis	17	51	32	0	0	3.85	0.7
15. Overall skill in providing end-of-life-care	15	51	34	0	0	3.80	0.7
16. Assessing and treating depression	15	45	40	0	0	3.75	0.7
17. Respecting resident's end-of-life preferences	19	38	41	2	0	3.74	0.8
18. Documenting resident's end-of-life preferences	5	62	33	0	0	3.71	0.6
19. Assessing and treating anxiety/restlessness	7	56	37	0	0	3.71	0.6
20. Assessing and treating constipation	23	25	53	0	0	3.70	0.8
21. Addressing spiritual needs	11	47	42	0	0	3.68	0.7
22. Assessing spiritual needs	8	43	50	0	0	3.58	0.6
23. Addressing end-of-life issues among culturally diverse residents and families	10	32	59	0	0	3.51	0.7
24. Assessing and treating nausea	10	30	60	0	0	3.50	0.7
25. Showing consistency among advance directives, physician notes, nursing notes and social service notes regarding end-of-life care	0	52	43	5	0	3.48	0.6
26. Assessing and treating dyspnea	5	38	58	0	0	3.48	0.6
27. Assessing and treating dry mouth	15	15	70	0	0	3.45	0.7

Six months after completing the two-day training in the year 2000, participants rated practice in their facility on 27 dimensions of care compared to practice before the training. Items are rank ordered by mean score where 5 = much better, 1 = much worse. SD = standard deviation.

TABLE 6. BARRIERS TO PROGRESS IN IMPROVING END-OF-LIFE CARE

	%				Mean	SD
	1 <i>Complete barrier</i>	2 <i>Major barrier</i>	3 <i>Minor barrier</i>	4 <i>Not a barrier at all</i>		
1. Lack of knowledge and skills in end-of-life care among staff	0	34	51	15	2.2	0.7
2. Inadequate staffing	0	30	51	19	2.1	0.7
3. Staff turnover	0	30	42	28	2.0	0.8
4. End-of-life issues not considered important by physicians	2	24	41	33	2.0	0.8
5. Poor communication among staff	0	7	72	21	1.9	0.5
6. Lack of resources for staff bereavement	2	21	31	45	1.8	0.9
7. Poor communication with residents/families	0	10	62	29	1.8	0.6
8. Lack of policies and procedures for end-of-life care	0	16	47	37	1.8	0.7
9. Fear of resident addiction to pain medication among residents and families	0	24	26	50	1.7	0.8
10. Fear of resident addiction to pain medication among staff	0	24	24	51	1.7	0.8
11. Lack of computers and other technology	0	14	26	60	1.5	0.7
12. Reluctance to involve hospice in residents' care	0	13	57	62	1.5	0.7
13. Lack of hospice resources	0	13	13	75	1.4	0.7
14. End-of-life issues not a priority in my facility	0	0	27	73	1.3	0.4

Participants rated each potential barrier based on their perception of its impact in their facility. Items are rank ordered by mean score where 4 = complete barrier, 1 = not a barrier at all. SD = standard deviation.

curriculum content and audience, dropping the 2-day model in favor of 1-day trainings offered in partnership with the American Society on Aging as well as shorter trainings targeting ombudsmen, nursing assistants, and nursing facility residents. The co-chairs of the workgroup, meanwhile, committed themselves to leading four year-long regional collaboratives on pain and pressure ulcers under the federal Nursing Home Quality Initiative. These collaboratives involved over 150 nursing facilities in a total of 6 days of offsite training, building on the lessons and relationships of the workgroup's nursing facility training. In 2002–2004 the workgroup focused on a new effort called *Promising Practices* with funding from the Archstone Foundation. This facilitated best practice model called for the workgroup to identify a select group of nursing facilities doing something particularly well in end-of-life care, provide technical assistance and mentoring to refine these practices into easily replicable models, and disseminate information about these practices statewide and nationally.

Challenges

Recruiting participants was more difficult in 2001 and 2002 than in 2000. Part of the difficulty with recruitment stemmed from increased financial and regulatory stresses on nursing facilities during this period, with generally negative impact on trainings throughout the industry. Getting staff to offsite trainings of any kind has become increasingly difficult. Feedback from some facilities suggested that they saw improving end-of-life care as optional, something to do if resources permitted and not to do in times of stress. Finally, outreach and advertising by the workgroup and Coalition partners were inconsistent. Workgroup members focused more on content development and quality of the training than on recruitment. In 2003 and 2004 the workgroup chose not to offer 2-day trainings so as not to compete with the regional collaboratives described above. Instead the Coalition has offered 1-day trainings in conjunction with conferences of the American Society on Aging. In 2004 the Coalition worked with the California Association

of Homes and Services for the Aging to design 2-hour sessions for the organization's newly developed nursing assistant and resident/consumer seminar tracks.

Participants in the workgroup have generally concurred that nursing facilities are experiencing crisis on multiple levels: finances, quality, public perception, staffing, and staff morale. The 2001 Institute of Medicine report on quality in long-term care confirmed what workgroup members already knew, that nursing facilities do not have adequate resources—or more broadly, the organizational capacity—to achieve mandated standards of care.⁶ On the other hand, the workgroup's end-of-life focus afforded participants the opportunity to pursue goals they felt passionately about and to articulate a positive vision. Beyond participants' personal commitment to improving end-of-life care, they viewed this compassion-driven focus as a vehicle to improve the quality infrastructure in nursing facilities. Workgroup participants and leaders within nursing facilities recognized the nursing facility crisis as a threat but have demonstrated that crisis can also be an opportunity to re-articulate broad visions and clear priorities, take risks, and network.⁷

The Nursing Facility Workgroup has had difficulty at times sustaining the volunteer efforts of its busy professionals. Throughout 1999–2001 the workgroup was able to pay only one of its leaders for regular part-time consulting. Curriculum development largely occurred during evenings and weekends, sustained by e-mail communication. Up to eight of the workgroup members helped lead each of the 2-day trainings, either donating their time or being supported, more or less formally, by their workplaces.

The workgroup has prioritized developing products and programs and stakeholder consensus rather than research and publications. Academic projects by workgroup members.^{8–11} have complemented and strengthened the work of the Nursing Facility Workgroup, but more publications, earlier in the group's development, could have garnered more visibility, credibility, and resources. The Coalition budgeted a small sum for professional assistance with evaluation, and the workgroup's training evaluation instrument performed well in 2000, contributing to significant improvements in the training.

ROLE OF PARTNERSHIP STRUCTURE AND FUNCTION IN THE PROJECT

The success of the Nursing Facility Workgroup has depended on a personal network developed over an extended period. The senior attorney representing the state's licensing agency has brought expertise and personal commitment to collaborative work on end-of-life issues since the 1980s. Given the usual turnover in government agencies, her presence has been important in conveying the state's sustained commitment to this area, and her expertise has calmed participants' legal and regulatory concerns. The workgroup's lead physician and nurse-educators have been involved in similar statewide nursing facility initiatives for a decade. The workgroup has grown to 30 members of whom approximately 10 attend each of the three or four face-to-face meetings each year. A little more than half¹⁸ form an active core group: 13 contributed content to the curriculum; half participated in the ECHO Long-Term Care Task Force; 16 have worked collaboratively on projects not related to end-of-life care.

Critical to the success of this largely volunteer workgroup has been the ability to pay for a minimal infrastructure: both the part-time workgroup leader/content expert and the part-time support staff. The latter performed all the meeting planning functions and website maintenance. The visible buy-in and contributions of the state's licensing agency have been critical to the group's consensus and credibility.

While grants from the CSP, the Archstone Foundation, and others have allowed the Coalition to pay for part-time administrative support and part-time leadership, in-kind support has been essential and not always easy to sustain. CHA has continued its generous in-kind support, but for a variety of reasons the in-kind support from several other organizations has fallen off. Our experience suggests that organizations are limited in what they can and will contribute "in kind" and that even small payments to partners and leaders help to sustain efforts.

LESSONS FOR OTHERS

The experience of the California Coalition for Compassionate Care reflects the small but useful

literature gleaned from experienced coalition leaders¹²⁻¹⁵:

- Coalitions are personal. They grow out of and are sustained by personal relationships and trust. The shared vision and goals must motivate participants to give their personal time and effort and/or to carve out time from competing work priorities. Organizations donate in-kind support only after individuals have argued for it in executive meetings.
- Leadership matters. Leaders must bring talent, content expertise, and personal networks to the table. They can bring some of this themselves, but more importantly they must recruit and nurture other leaders. Continuity of leadership stabilizes the personal networks.
- Products help. Product creation—paper and electronic materials and training programs, for instance—keeps the group focused on useful tasks, provides tangible benefits, and builds credibility.
- Infrastructure creates readiness. Both insiders and newcomers need to know whom to call, who performs which roles. Regular meetings and regular communications promote stability. Given a credible infrastructure, new opportunities will arise.
- Build in as much hands-on consultation as possible.
- Seek and build on short-term successes within a long-term strategy.
- Attend to personal networks and infrastructure, as noted above.
- Develop curricula and offer trainings in concert with licensing agencies.
- Budget adequately for evaluation.
- Include seed money for research, if possible.

CONCLUSIONS AND IMPLICATIONS

Several factors appear to have been critical in advancing an end-of-life agenda in California nursing facilities. First was the existence of a community of stakeholders and end-of-life activists who agreed that change was needed, who found common ground, and who recognized that it was in their multiple interests to work collaboratively to achieve change. Second, funding created a stable infrastructure. Third, targeting a small number of facilities with an organizational change strategy is more productive than trying to blanket the state with a one-day educational program. A strategy of educating individual clinicians fails to account for the difficulties these clinicians will have putting their knowledge into practice,¹⁸ particularly in nursing facilities. The hands-on guidance provided by the workgroup members during and after trainings has helped facility staff address the significant barriers to reform that exist in nursing facilities. With more funding, the workgroup would have increased its follow-up conference calls, reunions and consultations.

For statewide end-of-life coalitions, it appears critical to pursue several parallel initiatives that can share momentum, help each other past difficult periods, and create fruitful synergies. In particular, California's public engagement initiative and its high-energy local community coalitions have provided vision, motivation, personnel, and products.

Quality improvement approaches can lead to better processes and outcomes in end-of-life care.¹⁶ Improvement efforts in nursing facilities, however, are not likely to succeed without accounting for thin resources, turnover at every level, and lack of a quality management infrastructure in most facilities.¹⁷ The experiences of the Coalition's Nursing Facility Workgroup suggest that these efforts should:

- Anticipate and accommodate barriers and setbacks.
- Devote ample time to the fundamentals of quality improvement and organizational change.

The Coalition's efforts to achieve synergistic benefits among its various efforts have borne fruit. When California's new Health Care Decisions Law went into effect in July 2000, the Coalition developed consensus interpretive publications used by many of the state's major stakeholders. All of the workgroups have contributed to and used the Coalition's publications on advance care planning. Several members of the Nursing Facility Workgroup participate in local end-of-life coalitions, which are supported by the Public Engagement Workgroup. The Coalition's hospital project, California Hospital Initiative in Palliative Services (CHIPS), drew from the Nursing Facility Workgroup in designing its 2-day training and follow-up, then influenced the nurs-

ing facility training in turn. In local communities with both hospital and nursing facility participation, the interplay has been helpful to both efforts. Similarly, physicians and nurses have carried benefits from the Coalition's professional trainings (Education for Physicians in End-of-Life Care,¹⁹ Pain Resource Nurse Training,²⁰ End-of-Life Nursing Education Consortium²¹ into the nursing facility setting.

In spite of the barriers and without additional staff, some California nursing facilities succeeded in improving pain management and advance care planning because of the Coalition's efforts. These successes, lessons, and relationships continue to serve leaders interested in improving end-of-life care and overall quality in California's nursing facilities.

REFERENCES

1. ECHO (Extreme Care, Humane Options) Project: *Community Recommendations for Appropriate, Humane Medical Care for Dying or Irreversibly Ill Patients*. Sacramento Healthcare Decisions, 1997.
2. Finding Your Way. Sacramento Healthcare Decisions, 1998. (www.sachealthdecisions.org) (Last accessed July 15, 2004).
3. ECHO Long-Term Care Task Force: ECHO Nursing Facility Recommendations. California Coalition for Compassionate Care, 1999. Available at (www.finalchoices.calhealth.org) (Last accessed July 15, 2004).
4. American Medical Directors Association (AMDA) Palliative Care Curriculum. Piloted December 2002 and presented at AMDA annual seminars March 2003 and March 2004.
5. (www.finalchoices.calhealth.org) (Last accessed March 3, 2005).
6. Institute of Medicine Report: *Improving the Quality of Long-Term Care*. Washington, D.C.: National Academy Press, 2001.
7. Pettigrew A, Ferlie E, McKee L: *Shaping Strategic Change*. London: Sage Publications, 1992.
8. Post LF, Mitty EL, Bottrell MM, Dubler NN, Hill T, Mezey MD, Ramsey G: Guidelines for end-of-life care in nursing facilities: Principles and recommendations. *NAELA Quarterly* 2001;14:24–30.
9. Cadogan MP, Schnelle JF, Yamamoto-Mitani N, Cabrera G, Simmons SF: A minimum data set prevalence of pain quality indicator: Is it accurate and does it reflect differences in care processes? *J Gerontol A Biol Sci Med Sci* 2004;59:281–285.
10. Cadogan MP: Assessing pain in cognitively impaired nursing home residents: The state of the science and the state we're in. *J Am Med Dir Assoc* 2003;4:50–51.
11. Cadogan MP, Schnelle JF, Al-Sammarrai NR, Yamamoto-Mitani N, Cabrera G, Osterweil D, Simmons SF: A standardized quality assessment system to evaluate pain detection and management in the nursing home. *J Am Med Dir Assoc* 2005;6:1–9.
12. Dluhy MJ: *Building Coalitions in the Human Services*. Newbury Park: Sage Publications, 1990.
13. Taylor-Powell E, Rossing B, Gran J: *Evaluating Collaboratives: Reaching the Potential*. Madison: University of Wisconsin-Extension, 1998. (commerce.uwex.edu) (Last accessed July 15, 2004).
14. Ohio Center for Action on Coalition Development: *Building Coalitions*. Columbus: Cooperative Extension Service, Ohio State University, 1992. (ohioline.osu.edu/lines/kids.html) (Last accessed July 15, 2004).
15. Keith J: *Building and Maintaining Community Coalitions On Behalf of Children, Youth and Families*. National Network for Collaboration. (crs.uvm.edu/ncco/collab) (Last accessed July 15, 2004).
16. Lynn J, Schuster JL, Kabcenell A: *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians*. Oxford: Oxford University Press, 2000.
17. Weissman DE, Griffie J, Muchka S, Matson S: Building an institutional commitment to pain management in long-term care facilities. *J Pain Symptom Manage* 2000;20:35–43.
18. Weisfeld V, Miller D, Gibson R, Schroeder SA: Improving care at the end of life: What does it take? *Health Affairs* 2000;19:277–283.
19. Education for Physicians in End-of-Life Care. (www.epec.net) (Last accessed July 15, 2004).
20. Pain Resource Nurse Training. (www.cityofhope.org/prc/nurseknow.asp) (Last accessed July 15, 2004).
21. End-of-Life Nursing Education Consortium. (www.aacn.nche.edu/el nec) (Last accessed July 15, 2004).

Address reprint requests to:
Terry Hill, M.D.
Lumetra
One Sansome Street
San Francisco, CA 94104

E-mail: thillmd@pacbell.net