
Advancing the Palliative and End-of-Life Care Movement in Colorado

Recommendations

prepared by
The Planning Committee to Advance
the Palliative and End-of-Life Care
Movement in Colorado

with the assistance of
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Advancing the Palliative and End-of-Life Care Movement in Colorado: Recommendations

Executive Summary

Rose Community Foundation provided funding to convene a Planning Committee to Advance the Palliative and End-of-Life Care Movement in Colorado in August 2003. The Planning Committee was charged with developing, over a six-month period, a detailed list of recommended projects for advancing the palliative and end-of-life care movement in Colorado. This report sets forth those recommendations, which are presented in priority order at the end of this Executive Summary.

The Planning Committee based its work, in part, on the findings of a 2003 report, “Feasibility Study Concerning the Creation of a Colorado Center for End-of-Life and Palliative Care.” The report, funded by Bonfils-Stanton Foundation and Rose Community Foundation, identified the following as critical needs in Colorado’s end-of-life care system:

- More patient, family and public education.
- More/better health professionals training and education.
- Better reimbursement and relaxation of stringent rules.
- More family and caregiver support.
- Improved access to palliative and end-of-life care services.
- Identification of a locus of responsibility for filling gaps in and monitoring and improving the system.
- Changed attitudes about and a change in the culture around death and dying.

With more people living longer with terminal conditions, the Planning Committee focused on the need to ensure that Colorado has a comprehensive, accessible end-of-life care system in place that can provide quality, patient-centered care and address the patient’s and family’s spiritual, physical, emotional and practical needs.

Planning Committee members included nurses, hospice providers, a physician, a bioethicist, and insurance company, business community, AARP, minority community, church and patient representatives.

It is important to note that although the project proposals in this report are presented in rough priority order, the Planning Committee believes that all of the projects are important and should be funded. Generally, the committee recommends the following plan of action. First, a viable, statewide coordinating entity should be established. Second, projects that promote public awareness and education should be

pursued. Third, projects that support the social structures necessary to support quality end-of-life care should be implemented. It should also be noted that the list of recommended projects included in this report is not exhaustive. Rather, the recommended projects should be viewed as a starting point for moving the conversation forward.

Prioritized List of Recommended Projects

- A. Collaboration: Establish an independent, statewide partnership organization--along the lines of the Kansas LIFE Project--dedicated to improving access to quality end-of-life care in Colorado and fostering cooperative working relationships among those involved in hospice and palliative care.
- B. Information: Establish an easily available resource (e.g., Web site, resource guide) where anyone can get end-of-life information when they need it--a “just-in-time” resource with both local and state information.
- C. Provider Training: More widely disseminate existing modules/training programs for practicing physicians, nurses, clergymen, and pharmacists. Develop training programs for social workers and allied health professionals (e.g., home health professionals). Enhance ability and opportunities to train existing practitioners. Pay for training and education program.
- D. Advance directives: Take steps to make sure advance medical directives are executed and communicated.
- E. Access: Identify ways to enhance access to hospice and palliative care for those in need, especially in underserved urban and rural areas of the state.
- F. Public Education: Provide additional patient, family and caregiver education. Also, enhance support for and partner with families and caregivers.
- G. Chronic Care: Focus on interface/transition between disease management for chronic conditions and palliative care for those with incurable, ultimately fatal, chronic disabling illnesses (e.g., COPD, diabetes).
- H. Public Awareness: Develop a public awareness campaign. Work to change society’s attitudes about hospice and palliative care, and death and dying.
- I. Medical Education: Make palliative care a more substantial part of medical education.
- J. Payment: Address insurance industry and reimbursement issues, in part through pilot programs.
- K. Student Training: More widely disseminate existing modules for in-school and in-the-field (on-site) end-of-life care training for students in medical, nursing, pharmacy, social work, theology/divinity and other health care schools.
- L. Cultural Issues: Educate and develop programs to increase the level of cultural competency for people providing palliative and end-of-life care services. Develop strategies for addressing issues of access, health disparity and quality of care with diverse communities incorporating cultural knowledge. Develop standards for linguistically competent services.
- M. Field Education: Increase capacity for hospices and palliative care centers to provide field education to students—oversight, supervision, and training the trainers.

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* Effective December 2003, Pat Crawford left Centura Health. At that time Nancy Roth took her place on the Planning Committee.

Advancing the Palliative and End-of-Life Care Movement in Colorado: Recommendations

Introduction and Background

Rose Community Foundation provided funding in August 2003 to convene a Planning Committee to Advance the Palliative and End-of-Life Care Movement in Colorado. The committee was charged with developing, over a six-month period, a detailed, action-oriented set of recommended projects for advancing palliative and end-of-life care in Colorado that includes project priorities and a plan for each priority project. This report sets forth the committee's recommendations.

The recommendations included in this report were developed as a follow-up to a feasibility study conducted by Yondorf & Associates, a Denver-based health policy consulting firm, for Bonfils-Stanton Foundation and Rose Community Foundation. Completed in 2003, the "Feasibility Study Concerning the Creation of a Colorado Center for End-of-Life and Palliative Care" made a series of findings and recommendations. One of the study's main recommendations concerned the convening of a group of interested parties:

As a first step towards improving Colorado's end-of-life and palliative care system, a meeting of key players in the system should be convened to identify how their efforts could best be coordinated and expanded upon to address system needs, including filling service and program gaps.

Accordingly, Rose Community Foundation provided funding to hire Yondorf & Associates to convene a diverse group of community leaders interested in the provision of quality, accessible palliative and end-of-life care services to all Coloradans. The Planning Committee to Advance the Palliative Care and End-of-Life Care Movement in Colorado included nurses, hospice providers, a physician, a bioethicist, and insurance

Rose Community Foundation

Rose Community Foundation was established in 1995 to help make the Greater Denver community a vibrant and healthy place to live. The Foundation concentrates its resources in five key program areas: Aging, Child and Family Development, Education, Health and Jewish Life. It makes grants in seven counties: Adams, Arapahoe, Boulder, Broomfield, Denver, Douglas, and Jefferson. In 2003, the Foundation granted almost \$8 million. In addition to providing financial support to community institutions and nonprofit organizations, the Foundation also provides a flexible vehicle for donors to contribute to charitable causes.

At the heart of Rose Community Foundation's work is a spirit of caring, a commitment to excellence and a dedication to the principle of nondiscrimination. The Foundation thrives on creating strong relationships for positive change. Its motto is "building community together." The Foundation joins with many community partners to help people make better lives for themselves and to make our whole community strong and healthy.

company, business community, AARP, minority community, church and patient representatives. (See list of Planning Committee members on page 6.)

The Planning Committee met monthly between September 2003 and January 2004. The purpose of the meetings was to:

1. Develop a prioritized list of projects that are critical to advancing the end-of-life care movement in Denver and across Colorado; and
2. For each priority project, collectively create and design a plan with goals, objectives, activities/action steps, responsible parties, time frame, budget and measures of success.

The Planning Process

The Planning Committee began its work by reviewing its charge and the events that led to the formation of the committee. Based on this review, it developed the following mission statement:

Planning Committee Mission Statement
The mission of the Planning Committee is to advance the palliative and end-of-life care movement in Colorado by recommending a prioritized list of discrete, time-limited projects/action steps designed to fill gaps in, improve the quality of, and ensure barrier-free access to quality palliative and end-of-life care in Colorado.

The Planning Committee then took an in-depth look at the findings of the feasibility study, paying particular attention to the study's system-wide needs assessment. The assessment identified the most critical needs in Colorado's end-of-life system, which the Planning Committee adopted as the goals for its planning process:

Critical Needs in Colorado's End-of-Life Care System
<ul style="list-style-type: none">• More patient, family and public education.• More/better health professionals training and education.• Better reimbursement and relaxation of stringent rules.• More family and caregiver support.• Improved access to palliative and end-of-life care services.• Identification of a locus of responsibility for filling gaps in and monitoring and improving the system.• Change in attitudes and the culture around death and dying.

The Planning Committee also discussed and agreed on the following as the overall objectives for the planning process:

Planning Committee Objectives
<ul style="list-style-type: none">• All Coloradans facing death should be able to have a “quality dying experience.” This means unimpeded, convenient access to appropriate, patient-directed end-of-life care and culturally appropriate services that address the patient’s spiritual, physical, emotional and practical needs.• All Coloradans should be able to get palliative care when they need it, regardless of their prognosis.• Everyone who is an appropriate candidate for hospice care should have this option and be alerted to this option in a timely manner.• People should be entitled to and supported in maintaining control of their own care, to the extent they are able, throughout their dying experience.• With respect to issues around death and dying, physicians and other providers, patients, families and the public in general should be knowledgeable about, attentive to and make use of community resources to help them.

The Planning Committee began the process of identifying possible projects (which it views as action steps) by brainstorming a long list of possible ideas. In some cases, committee members and outside experts made presentations to the Planning Committee about model programs. Committee members and Yondorf & Associates also researched and shared information about programs in other states.

Over several meetings, the Planning Committee refined its list of projects, narrowing it to the 13 proposals described in the next section of this report. Criteria used by the committee to develop the group’s final list of proposals included:

Main Criteria Used to Decide on Recommended Projects
<ul style="list-style-type: none">• Substantially furthers one of the identified objectives.• Meets a critical need identified in the feasibility study.• Builds on current efforts, leveraging existing resources wherever possible.• Has been demonstrated to be a successful approach or has a strong likelihood of success.• Has significant potential for sustainability.• Has the support of the full Planning Committee.

In the course of discussions about the project proposals, Planning Committee members made special note of several important points:

- In many cases good resource materials and educational programs on hospice and palliative care and end-of-life issues already exist, but people don't know about them or they are not easily accessible.
- The palliative and hospice approach to care needs to be made available earlier in the illness trajectory than during the last six months of life.
- Physicians in particular and the public in general need to see hospice and palliative care as something other than brink-of-death care.
- Themes that should be carried through all projects include:
 - Cultural competency,
 - Changing attitudes about death and dying,
 - Improving access to hospice and palliative care, and
 - Creating and maintaining a high standard of quality for end-of-life care.

The next step was for the committee to flesh out the proposals. The Planning Committee agreed to include the following information for each of the proposal write-ups:

Elements of Recommended Project Descriptions
<ul style="list-style-type: none">• Problem statement.• Project description and specific deliverables.• Information on similar projects elsewhere in the country.• Evaluation plan.• Type of entity that might carry out the project.• Approximate number and types of paid staff needed for the project.• Ballpark project cost estimate and budget assumptions.• Length of time needed to complete the project.

In some cases, the Planning Committee was unable to fill out all of the elements of each proposal, largely due to time constraints.

Next, the Planning Committee took up the task of prioritizing its list of proposals. The committee began the prioritization process by having each member fill out a ballot. The group discussed the results and then came to the consensus ranking shown on page 5. The committee used the following criteria to prioritize the projects:

Criteria for Prioritizing Recommended Projects

- Serves as a foundation building block for other programs.
- Greatest likelihood of improving quality of and access to end-of-life care.
- Most feasible, sustainable.
- Ability to reach/affect major target audiences.
- Cost-effectiveness.
- Need.

It is important to note that, although the project proposals in this report are presented in rough priority order, the Planning Committee believes that all of the projects are important and should be funded. Generally, the committee recommends the following plan of action:

1. Establish a viable, statewide coordinating entity.
2. Fund projects that promote public awareness and education.
3. Implement projects that support the social structures necessary to support quality end-of-life care.

The committee understands that some funders may be more interested in some of the proposals than others, based on their own funding priorities. Funders are encouraged to consider supporting those projects that are of most interest to them, regardless of priority order. The purpose of prioritizing the proposals is to offer guidance to organizations interested in knowing what a group knowledgeable about the end-of-life system in Colorado thinks are the most important projects.

Finally, it should be noted that the list of suggested projects presented in this report is not an exhaustive list. Rather, it represents the Planning Committee's best assessment of the projects that would do the most, in a relatively short time frame, to improve the quality of and access to palliative and end-of-life care in Colorado. The recommendations are designed to start the conversation moving forward.

Recommended Projects

- A. Collaboration: Establish an independent, statewide partnership organization--along the lines of the Kansas LIFE Project--dedicated to improving access to quality end-of-life care in Colorado and fostering cooperative working relationships among those involved in hospice and palliative care.**

Problem statement:

- There is no locus of responsibility for monitoring, improving, evaluating, and filling gaps in Colorado's end-of-life system as a whole.
- There is no single, unified voice in the state advocating on behalf of individuals and groups concerned about quality end-of-life and palliative care for all Coloradans.
- Colorado does not have a statewide, collaborative organization that can work to advance the hospice and palliative care movement in Colorado and enhance the ability of its member organizations to work together and make maximum use of limited resources.

Project description and specific deliverables:

- Establish a broad partnership/coalition arrangement. The arrangement should take the form of a 501(c)(3) nonprofit organization that has wide community involvement—not just the traditional players. The new organization should focus on public policy, professional education and public education. The Planning Committee recommends modeling the arrangement after the Kansas LIFE Project and Utah's End-of-Life Partnership (see descriptions below). Among other things, the partnership organization should:
 - Coordinate advocacy on end-of-life issues;
 - Sponsor broad public education efforts;
 - Partner on training and educational efforts for professionals providing end-of-life and palliative care services;
 - Partner on research projects;
 - Assure sustainability by securing funding for specific, discrete projects and pursuing member donations; and
 - On an ongoing basis, once they have been set up, update the Web site and resource guide on end-of-life and palliative care described under project B.

Is something similar being done elsewhere in the country?

Yes. In addition to the state centers for end-of-life and palliative care described in the

Yondorf & Associates study, “Feasibility Study Concerning the Creation of a Colorado Center for End-of-Life and Palliative Care,” Kansas and Utah have model programs.

- The Kansas LIFE (Living Initiatives For End-of-Life Care) Project has more than 100 partners, including state agencies, academic institutions, consumer advocacy groups, individual cities, towns and counties, medical centers, pain protocol project facilities, professional associations, and funders. Its mission is to help all Kansans live with dignity, comfort and peace as they near the end of life. The LIFE Project grew out of a meeting of interested stakeholder organizations convened by the Kansas Association of Hospices in 1998. Examples of some of its projects include:¹
 - Addressing public policy issues (e.g., advance care planning, pain management and guardianship);
 - Staffing a toll-free consumer information HelpLine;
 - Sponsoring a pain management hotline;
 - Developing a public awareness campaign, supported by the Kansas Association of Broadcasters, about the issues facing Kansans nearing the end of life;
 - Sponsoring educational events and speakers for providers;
 - Managing a bi-state telehospice project;
 - Launching a public service campaign, “Every Kansan should expect good pain management!”; and
 - Launching a Web site for the public, providers and its partners (www.lifeproject.org).

- Utah’s Partnership to Improve End-of-Life Care is a coalition of volunteers--both individuals and organizations--who are interested in combining their efforts and expertise to plan and implement changes to improve care for persons near the end of life and their families. The partnership has agreed to work toward four objectives:
 - Engaging the public in discussions about the end of life in town meetings and dialogue to action programs;
 - Improving professional practice in end-of-life care;
 - Educating patients and their families about end-of-life care and related resources; and
 - Serving as a resource to policy makers.

Its Web site covers the following topics: care options, pain/symptoms, support, dying process, end-of-life law, after death, books, and children.²

Evaluation plan (how will we know if the project was successful, made a difference?):

- Document activities.

¹ For more information, see the Kansas Life Project Web site: <http://www.lifeproject.org>.

² For more information, see the End-of-Life Partnership web site: <http://www.carefordying.org>.

- Track number of Web site hits, phone calls.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organizations.
- Local hospice(s)
- Other local association(s).
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other

Note: The Colorado Hospice Organization recently indicated its intent to form a new partnership organization. It intends to work with interested members of the Planning Committee as well as other interested groups to form this new organization and secure seed money.

Approximate number and types of paid staff needed for this project:

Initially, formal staffing for the basic operations of the partnership organization might be minimal—perhaps 1.0 FTE to establish the organization, coordinate meetings, dispense checks, take minutes, etc. Other staff would be hired/paid for on a project-specific basis and might be housed at the office of the lead organization for that project (e.g., UCHSC, Alzheimer’s Association, etc.).

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000 (seed money)
- More than \$100,000

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years (Note: After a couple of years, funding for administration of the organization might come from indirect cost charges out of project grants and partner donations.)³
- More than 3 years

³ Funding for the Kansas LIFE Project comes from The Robert Wood Johnson Foundation, United Methodist Health Ministry Fund, American Express Financial Advisers, Boehringer-Ingelheim, Foundation for Hospice Care, Kansas Association of Broadcasters, Kansas Press Association, Purdue Pharma, several regional medical centers and hospices, and the U.S. Department of Commerce (telehospice project).

B. Information: Establish an easily available resource (e.g., Web site, resource guide) where anyone can get end-of-life information when they need it--a “just-in-time” resource with both local and state information.

Problem statement:

- Currently there is no central source of information about the array of end-of-life care resources in Colorado.
 - There is a need for a central source of information for professionals as well as consumers.
 - Professionals, patients, families and caregivers need to know when palliative care is best used, at what levels, and the options available.
 - More information is needed on who exactly provides what. For example, some hospices and hospitals provide a wide range of services, others don't. Some entities specialize in certain types of palliative care (e.g., pediatric palliative care); others provide more general care only.
 - People need to know where they can go to get information about the effectiveness of various end-of-life care interventions.
 - Once a comprehensive, central information source has been established, it needs to be marketed so that people know it exists and use it.

Project description and specific deliverables:

Establish a Web-based, statewide, comprehensive end-of-life information resource center

- The Web site would be updated on a regular basis, contain a search engine to easily find relevant, specific information, and contain contact information for the webmaster for additional questions, updates, or concerns.
- The Web site would provide the following services for consumers:
 - Contain information to assist consumers in identifying service providers in their geographic location;
 - Be a resource that tells which providers (e.g., hospices, hospitals, palliative care services, etc.) offer what specific services (e.g., complimentary, alternative, inpatient, home, or group care, consulting services, etc.);
 - Contain information to assist consumers in choosing between similar programs (e.g., choosing between several hospices, selecting a durable medical equipment supplier, finding the most appropriate support group, etc.); and
 - Have information on the Web site in English and Spanish.
- The Web site would provide the following services for health care professionals:

- Link to the professional literature;
 - Link to relevant research; and
 - Link to relevant research tools.
- The proposed Web site would include the following palliative and hospice care information:
 - Updating and maintaining the 1998 “A Colorado Resource Guide for End-of-Life Care.” This resource guide is currently available online at <http://www.cdphe.state.co.us/hf/static/hospice.htm>, however it has not been updated since 1998. The guide includes the following information by county:

<ul style="list-style-type: none"> ▪ Adult day programs ▪ Bereavement support resources ▪ Community mental health clinics ▪ County health departments ▪ Funeral homes and mortuaries ▪ Home health agencies ▪ Hospice programs ▪ Hospitals (general) ▪ Medical society ▪ Senior and disabled services ▪ National health organizations and resources contact information 	<ul style="list-style-type: none"> ▪ Toll free numbers for health information ▪ The project would also add the following information: <ul style="list-style-type: none"> - Bereavement and grief support resources - Family and caregiver support resources - Resources specifically designed for certain target populations (e.g., racial, ethnic or sexual minorities)
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Put together a consumer resource guide (paper not Web-based)

- A detailed resource guide would be developed, much like the new DRCOG (Denver Regional Council of Governments) Caregiver Handbook but focused on end-of-life, grief and loss issues. The Alzheimer’s Association has had great success with a training program for caregivers that includes a CD they take home and use over the years as their needs change.
- The project would explore best ways to make sure people know about and receive the guide when they need it—namely when they get a prognosis that is terminal.

Is something similar being done elsewhere in the country?

Yes. See for example, the Utah End-of-Life Care Partnership Utah Web site: www.carefordying.org. Also, the Colorado Collective for Medical Decisionmaking put together a resource guide five years ago, which could serve as the basis for writing an up-to-date guide.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization. Examples:
 - Local hospice(s)
 - Other local association(s).
 - University of Colorado Health Sciences Center or medical school
- Consultant
- Other:

Approximate number and types of paid staff needed for this project:

This project might be done by a consultant or could take between 0.5 and 1.0 FTE in the first year.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000—(Second and third years)
- \$50,001 - \$100,000--(First year)
- More than \$100,000

Assumes the major work of pulling together materials and organizing the Web site and resource guide would occur in the first year. Over the next two years, missing materials would be added and the Web site and resource guide would be refined and updated. In subsequent years, a limited budget would be needed to keep the site and guide updated and to reproduce the guide for those without access to a computer or who need a hard copy of the entire document.

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

Other comments:

- Permission has been granted to update the document, “Colorado Resource Guide for End-of-Life Care,” originally compiled in 1998 by the (now defunct) Colorado Collective for Medical Decisionmaking.

C. Provider Training: More widely disseminate existing modules/training programs for practicing physicians, nurses, clergymen, and pharmacists. Develop training programs for social workers and allied health professionals (e.g., home health professionals). Enhance ability and opportunities to train existing practitioners. Pay for training and education program.

Problem statement:

- There are well-documented gaps in health care practitioners' knowledge of quality end-of-life care. In particular, more practicing physicians need end-of-life care training.
- In some cases providers realize they have gaps in their knowledge and need to be provided with the opportunity and means to learn what they need to know. In other cases providers need to be convinced that there is value-added for their practices in getting trained.
- There are quality educational programs and modules for some providers (especially for physicians and nurses) but not for all providers (e.g., materials for social workers are being developed, more needs to be done for allied health professionals). However the existing programs may not always be user-friendly (e.g., nurses can't get away from their jobs long enough to get, or can't afford the full cost of, ELNEC (End-of-Life Nursing Education Consortium) training).
- Different provider groups need to hear the same basic messages. Steps need to be taken to see that training on end-of-life issues is consistent across the health care professions.

Project description and specific deliverables:

- Approach trainers to motivate them to get end-of-life care training and to use the modules. The project would educate hospitals, directors of nursing, county medical societies, faith-based communities and others on the value of training.
- Develop, distribute and get media attention for report cards on percent of health professionals exposed to end-of-life curricula. The project would set specific targets for a two-year period (e.g., expose 30% general internists, 75% hospitals have integrated end-of-life care training into their regular curricula, etc.).
- Engage in a full-court press over the course of two years to get more nurses and clergymen trained by providing funding to underwrite the cost of training and to get out the word about the availability and value of the training.
 - Use ELNEC materials. In other parts of the country, ELNEC trainings have been held that include social workers, chaplains, nurses aides and others, in addition to nurses. Consider reaching out to home health agency providers.

Kaiser/Denver has also done two successful rounds of ELNEC trainings for its staff that involved a multi-disciplinary audience.

- Get funding to pay people to come (i.e., cover cost of training and training materials). (Note: average cost for training runs \$200-\$550 per person.)
- Consider having 1½ day training program—1 day ELNEC and another ½ day to train trainers and to have additional training targeted at social workers, chaplains, etc.
- Review existing training programs and adapt them, shorten them, and put them into manageable bite-sized chunks.
 - Consider ½ day training for busy chaplains, nurse’s aides and others who can’t get away for 1 or 1½ day training program. Adapt existing ELNEC materials.
 - Consider 1-day training in palliative care for nurses using the model developed by the National Cancer Institute R-25 grant—A Nursing Education Model: Palliative Care and Beyond Hospice—at the UCHSC School of Nursing⁴
 - Consider models used by some hospices. For example, HospiceCare of Boulder & Broomfield staff gets ELNEC end-of-life training in-house in monthly two-hour programs taught by staff that has been through the ELNEC train-the-trainers program. Hospice and Palliative Care of Western Colorado staff gets ELNEC training as part of their orientation, in a multidisciplinary setting.
 - Research training materials for spiritual care providers, identify best practices, and reach out to faith-based communities to use these materials. Assist trainers to adapt curriculum and plan education for spiritual care providers in their communities.
- Design an experiential train-the-trainer curriculum for chaplains and community clergy or, if it exists, adapt a successful program used in another part of the country.

Is something similar being done elsewhere in the country?

Yes, there are scattered examples across the country that Colorado could look to. Also, Alberta, Canada has done a province-wide education project.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Set specific targets for increasing the number of people who have taken an end-of-life care course/training.
- Develop a report card.
- Evaluate trainings and changes in participants’ knowledge, practice, and attitudes.

Type of entity that might carry out the project:

 X Colorado Hospice Organization

⁴ For more information, go to: <http://www.uchsc.edu/nursing/pallcare>.

- Other statewide organization. Example:
 - Colorado Council of Churches
- Local hospice(s)
- Other local association(s). Examples:
 - Interfaith Alliances
 - Hospice chaplains group
 - Recipients of Robert Wood Johnson Foundation Faith in Action grants
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Collaboration or association of seminaries in Colorado
 - ELNEC project office
 - In conjunction with local hospice or professional discipline programs

Approximate number and types of paid staff needed for this project:

Probably need 1 FTE to organize schedule, secure trainers and sites, etc., and promote involvement in training programs.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000
- More than \$100,000

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

D. Advance Directives: Take steps to make sure advance medical directives are executed and communicated.

Problem statement:

An advance medical directive is a document in which an individual sets forth his or her wishes in case of terminal illness or persistent unconsciousness where the individual is no longer capable of participating in his or her health care decisions. In Colorado there are two major problems regarding advance medical directives:

- First, most people have not executed an advance medical directive, even though it has been estimated that nearly 70% of Americans will, at some point in their lives, have to decide whether to withdraw life support. A study conducted in Denver found that among a study group of 1,302 people age 75 or older enrolled in Kaiser, just one in five had an advance medical directive in their medical record.⁵ This is a problem not only among the elderly and middle-aged adults but also among young adults. According to Glenn McGee, a bioethicist at the University of Pennsylvania, “Nearly 100% of people ages 18 to 30 have no written directives for their health care. But 80% of those who are now in a persistent vegetative state are in this age group.”⁶
- Second, providers don’t always know that their patient has an advance medical directive.

Project description and specific deliverables:

- Research what have been the most effective campaigns for increasing the proportion of the population with advance medical directives and replicate those campaigns in Colorado. Examples include:
 - Encouraging those who attend the annual 9Health Fair to sign an advance medical directive;
 - Encouraging more hospitals and health plans to distribute information about advance medical directives;
 - Adding a check-off to the back of drivers licenses to indicate whether a person has executed a directive; and
 - Including information on advance medical directives in high school and college “Preparing for Life” classes.
- Working through organizations representing gay, lesbian, bisexual and transgender people, encourage gay, lesbian, bisexual and transgender individuals to execute an advance medical directive that names an “agent” responsible for making medical care decisions in the event they are unable to do so. This is especially important where a partner rather than a biological family member is the person’s preferred agent.
- Investigate and seek to institutionalize best practices in terms of making sure that providers who need to know can easily determine whether a given patient has an advance medical directive and replicate in Colorado. Note: Dr. Terry Knapp, MD, Adjunct Faculty at the UCHSC Center for Bioethics and Humanities, made a presentation to the Planning Committee in which he proposed a creative, Internet-based solution to this problem. Under Dr. Knapp’s proposal, people would be able to write, edit and maintain advance directives on the Internet. The Web-based

⁵ Jonathan Betz Brown et al., “Practical Methods to Increase Use of Advance Medical Directives,” *Journal of General Internal Medicine* 14 No. 1 (January 1999). Web site: <http://www.blackwell-synergy.com/links/doi/10.1046/j.1525-1497.1999.00276.x/abs/>

⁶ “A ‘Vegetative State’ Poses Religious, Ethical Quandaries,” *USA Today*, October 27, 2003.

program would be available to the patient and his or her proxies and to all licensed health care providers and institutions.

Is something similar being done here or elsewhere in the country?

- Yes. For example, the State Bar of Wisconsin has developed “A Gift to Your Family.” This consumer guide serves as a tool for discussing future health care wishes and includes the state legal forms that enable people to put their wishes into writing.
- North Carolina passed legislation in 2001 (G.S. 130A-465) directing the state’s Department of Health and Human Services to establish a new online Advance Health Care Directives Registry for health care powers of attorney, living wills, and other advance health care directives.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Document the proportion of Colorado residents or the proportion of the population in a test area or seen in an emergency room or hospital who have advance medical directives, before and after the project.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organizations. Examples:
 - Colorado Hospital Association
 - Nursing home trade association
- Local hospice(s)
- Other local association(s). Examples:
 - University of Colorado Health Sciences Center or medical school
 - Consultant
 - Other:

Approximate number and types of paid staff needed for this project:

This will vary considerably depending on the particular approach that is taken. An enhanced outreach and education program may be accomplished with perhaps 0.5 FTE. Development of a Web-based solution to the problem that allows easy access to an advance medical directive by the patient, family and any treating physician could require hundreds of thousands of dollars in development costs.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000—(For an outreach and education project)
- \$50,001 - \$100,000
- More than \$100,000—(For a Web-based solution)

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years—(For an outreach and education project)
- More than 3 years—(For a Web-based solution)

E. Access: Identify ways to enhance access to hospice and palliative care for those in need, especially in underserved urban and rural areas of the state.

Problem statement:

- Some counties and parts of counties in Colorado do not have access to hospice care or providers with expertise in palliative care. Access to the full range of hospice services is also a problem in some urban areas.
- In some cases, skilled nursing facilities in underserved areas of the state are delivering palliative care but need assistance or training in pain and symptom control for those at the end-of-life.
- According to Growth House Inc., a San Francisco-based organization committed to improving care for the dying, “Two trends are on a collision course: the senior population is growing, while numbers of healthcare providers are increasingly stretched thin. This mismatch will force changes in the way care is provided to the chronically and terminally ill.” To address this problem, the National Hospice Work Group (NHWG) recommends funding of telehospice demonstration projects, in which centrally-located palliative care experts can interact both with family caregivers in home settings and with other health care providers. Such "virtual experts" can provide cost-effective consultation with staff in non-hospice inpatient settings such as hospitals, skilled nursing facilities, and assisted living centers.
- E-hospice and telehospice services managed by experienced hospice care providers could significantly aid those in under-populated areas.

Project description and specific deliverables:

- Enhance the ability of hospices in outlying parts of the state to expand their reach to underserved areas through the use of e-hospice and telehospice services to help provide such services as spiritual support, physicals, grief support, symptom management, etc. Also assist underserved urban areas.
- Coordinate with the University of Colorado Health Sciences Center to use the Area Health Education Center (AHEC) infrastructure to make this happen.

- Assist with the purchase of technology that could be used by rural hospices, patients, home health and skilled nursing facility providers in underserved areas to connect with experts via telehospice. Also provide training.

Is something similar being done here or elsewhere in the country?

- Yes. Hospice of Michigan is using telehospice services in both rural and urban settings:

Hospice of Michigan's "Telehospice" services use interactive video technology to connect hospice patients with Hospice of Michigan medical staff by way of regular telephone lines, a mini-video camera and television monitor. It supplements in-home hospice visits, making the Hospice of Michigan clinical teams available 24-hours-per-day for face-to-face consultations with patients and families. The goal of the project is to improve the level of care provided at the end-of-life and to address the barriers that exist to quality care in urban and rural areas, as well as economic and social barriers. Hospice of Michigan is using the Telehospice equipment with teams in urban metro Detroit, as well as rural communities in Northwestern Michigan.⁷

- Michigan and Kansas launched a joint telehospice project in 2000. Videophones were placed in the homes of hospice patients and hospice providers used this technology to supplement traditional care. Researchers found that patients and caregivers were “uniformly positive about the service and wish to see increased utilization within their own care plans.”⁸
- Centura Health is piloting a telehealth program for congestive heart patients in Colorado Springs. The goal of the program is to reduce hospitalizations and emergency room visits by providing more frequent monitoring. A nurse makes three video visits a week to each of the patients in the program. She communicates with patients via a moveable video camera, a small video screen, a microphone and speakerphone. Patients can have the following checked remotely: blood pressure, heart rate, breathing sounds, blood oxygen saturation, and weight.⁹
- The Colorado chapter of the Alzheimer’s Association and Kaiser Permanente have teamed up for a pilot, group telephone conferencing project for Alzheimer’s patient caregivers. Forty minutes of each call is devoted to training and 20 minutes to questions and answers. The program appears to be particularly attractive for caregivers who have difficulty leaving home for half-a-day or more to attend a centrally located training session. Approximately 70% of Alzheimer’s patients are cared for at home.

⁷ Source: <http://www.hom.org/mac/mactele.asp>

⁸ Pamela Whitten, Gary Doolittle and Seth Hellmich, “Telehospice: Using Telecommunication Technology for Terminally Ill Patients,” *JCMD* 6 No. 4, <http://www.ascusc.org/jcmc/vol6/issue4/whitten2.html>

⁹ Bill Radford, “Heart Patients Monitored Remotely,” *The Gazette*, December 27, 2003.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Determine level of services available in underserved areas before and after project.
- Assess patient and provider level of satisfaction with availability of services before and after implementation of telehospice services.
- For services targeted with telehospice (e.g., pain management, comfort care for those cared for at home, symptom management, etc.) do cost-benefit analysis of telehospice versus direct care provision in underserved areas.
- Use same evaluation model as that used for the Michigan/Kansas project described above.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization.
- Local hospice(s)
- Other local association(s). Examples:
 - Contracted home care agencies
 - Community nursing homes
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - VA hospitals
 - Hospital and community based clinics
 - Nursing homes
 - State veterans' homes
 - Colorado AHEC (Area Health Education Center)

Approximate number and types of paid staff needed for this project:

Estimate for first year = 0.5 FTE project administrator; 0.25 FTE evaluator. Also need to purchase equipment for placement in homes.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000—(Second year)
- \$50,001 - \$100,000—(First year)
- More than \$100,000

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

F. Public Education. Provide additional patient, family and caregiver education. Also, enhance support for and partner with families and caregivers.

Problem statement:

- Patients, families and caregivers need to know how to bring up their concerns/needs with the doctor.
 - Patients, families and caregivers can't rely on assumed "experts" (e.g., their doctor) to know everything; the patient needs to take charge.
- Patients, families and caregivers need to know enough to know they can ask for certain kinds of help (e.g., symptom management, palliative care, resources and services, etc.).
- Patients, families and caregivers need skills to navigate the system (e.g., "Death and Dying 101"—process, lingo, etc.).
 - Patients, families and caregivers need to know their rights.
 - Some groups are doing good education but it is not widespread. More educational opportunities are needed. Education is not done consistently—intense in some places with some groups, non-existent or extremely limited in other places. Additional ways to put materials in the hands of much, much larger groups need to be pursued.
- Patients, families and caregivers need to understand the progression of the patient's illness and needs and the options available at each stage.
- There are a lot of good resource materials, but too often the people who need them aren't getting them or don't know about them.
 - Best opportunity to intervene is in the physician's office, but not much in the way of education or provision of relevant materials occurs there.

Project description and specific deliverables:

Actively work to improve the broader dissemination and use of good existing educational and resource materials:

- Pilot the use of the interactive, educational CD-ROM entitled "Completing a Life." This educational tool assists people with terminal illness in addressing important end-of-life issues. It covers a wide range of information, spanning physical, emotional, family and spiritual issues.¹⁰
 - Pilot the CD-ROM in several physicians' offices in the metro Denver area and in a second non-urban area (e.g., southeast Colorado or Western Slope).

¹⁰ For more information, see Karen Ogle et al., "'Completing a Life:' Development of an Interactive Multimedia CD-ROM for Patient and Family Education in End-of-Life Care," *Journal of Palliative Medicine* 6, No. 5 (November 5, 2003). Also see the kff.org and carenet Web sites.

- Target primary care offices with large Medicare clientele—patients with heart disease, cancer, Alzheimer’s or other chronic conditions that are progressive and may be fatal.
 - Consider running the pilot in association with CareNet—a network of 31 private practices with 460 clinicians. CareNet has a practice-based research commitment.
- Work with physician groups, clinics and health plans to encourage providers to have in their waiting rooms and available to borrow the “Completing a Life” CD-ROM. Promote much broader distribution of the *Healthwise Handbook*. Bring people’s attention to the section, “Ask the Doctor Check List.” Also promote broader distribution of DRCOG’s excellent guide, “Caregiver Handbook: A Local Guide for Caregivers of Older Adults in the Denver Region” (Summer 2002).¹¹ Work with chronic disease groups.
 - Focus on one community—similar to Missoula, Montana model, to do a targeted educational effort and measure the impact.
 - Identify best end-of-life resources--this is key. Caregiving books are good up to a point, but often do an inadequate job of dealing with end-of-life issues. The project would identify the five best general resources and the best resources on particular end-of-life care issues. This information would be provided via a link on the Web site described in project B.
 - Educate physician office staff.

Is something similar being done elsewhere in the country?

- Yes. Colorado can adapt some of the successful initiatives in other parts of the country for application here.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Do a survey of palliative and hospice care users--how did you find out about palliative care, hospice care?
- Attach a feedback form to the materials that are distributed.
- Find out how families respond to the intervention.
- Ask point-of-service question of users (perhaps add questionnaire to CD-ROM).

Type of entity that might carry out the project:

Colorado Hospice Organization

¹¹ This handbook is a helpful and practical resource guide for caregivers. It includes information on nutrition, finances, insurance, medical concerns, and a host of other topics. An added feature is a list of Internet resources. There is no charge for the handbook.

- Other statewide organization. Examples:
 - Insurers, health plans
 - Alzheimer's Association
- Local hospice(s)
- Other local association(s). Examples:
 - Metro Denver End-of-Life Coalition
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Clinics and physician practices

Approximate number and types of paid staff needed for this project:

- 1.0 FTE first year to collect and pull together information, line up physician offices for pilot. Additional staff in years 2 and 3 to conduct pilot and do evaluation.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000
- More than \$100,000

- Need to figure in cost of purchasing books and CDs.
- Do pilot in Year 02. Evaluation of results in Year 03.

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

G. Chronic Care. Focus on interface/transition between disease management for chronic conditions and palliative care for those with incurable, ultimately fatal, chronic disabling illnesses (e.g., COPD, diabetes).

Problem statement:

- Disease management needs to have palliative care and the transition to hospice care built into the model. Disease management programs need to pay more attention to palliative care and have the information necessary to provide assistance when it becomes apparent that the illness or condition is moving towards its terminal stage.

- Current disease management programs tend to focus on a single disease, such as diabetes or asthma. But often those in the advanced stages of an illness have multiple chronic problems.

One in five Americans has multiple chronic conditions, most often hypertension, chronic mental conditions or respiratory disease. Five percent of the population has four or more conditions... these patients account for 26% of US health care spending and nearly 80% of total Medicare spending, according to 1999 data... [According to Dr. Gerard Anderson, professor of health policy at Johns Hopkins University,] “We've got to design reform around where 80% of the dollars are spent. It's the most important thing we can do.”¹²

- Basic competency in palliative care is needed for all disease managers, especially for those dealing with patients who have multiple, advanced chronic conditions.

Project description and specific deliverables:

- Add a palliative care component to existing cardiac care, COPD (chronic obstructive pulmonary disease), and diabetes disease management modules and pilot test in Colorado. The project would build on the work of American Healthways (see description below).
- Develop a training program on basic palliative care competency for disease managers. The program should recognize that while the main focus for a disease manager may be on a patient's most important or serious condition, attention must also be paid to the patient's palliative care needs—some of which (e.g., depression) may arise from secondary or complicating conditions.
- The modules would be developed in Phase I and pilot-tested and evaluated in Phase II.

Is something similar being done elsewhere in the country?

- Yes. American Healthways (a for-profit disease management firm) is working on the development of disease management programs for those with multiple advanced conditions. Palliative care-focused modules are also being developed and tested for renal conditions (Massachusetts), Alzheimer's disease (Chicago), HIV/AIDS (Louisiana), and congestive heart failure (San Francisco-Sutter Home Care and Hospice).
- Seven years ago, here in Colorado, the Alzheimer's Association and hospice teamed up to increase Alzheimer's patients' use of hospice care. The purpose of the project was to educate patients and their families earlier in the disease process as to how hospice could be a resource for them at various points in the disease process. The result was an increase from 1% to 10% of Alzheimer's patients using hospice. The Alzheimer's Association and hospice care providers are interested in significantly

¹² “Disease Management May Save Medicare Money—Expert,” *Reuters Health*, December 19, 2002, <http://12.31.13.115/HealthNews/reuters/NewsStory1219200235.htm>

increasing the use of hospice and palliative care services by Alzheimer's patients, especially since 70% of patients are cared for in the home.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Examine patient outcomes and patient and family satisfaction levels for a group using the newly developed disease management tools and a control group using current disease management tools. The average length of hospice utilization should increase and emergency room utilization and hospitalizations should decrease for the study group.
- Conduct a cost-benefit analysis to assess the added expense of using more refined disease management tools and the benefits (both qualitative and quantitative) measured in terms of such things as emergency room use, pain control, etc.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization. Examples:
- Local hospice(s)
- Other local association(s). Examples:
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Organizations providing or paying for care, such as insurance plans (e.g., Colorado Access, Medicaid, Kaiser) in collaboration with the VA, Children's Hospital, local hospices, etc.

Approximate number and types of paid staff needed for this project:

- Phase I: Project director and expert consultant to research and put together modules and set up pilot sites.
- Phase II: 2 case managers plus evaluation component.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000 –Year 01
- More than \$100,000—Years 02 and 03 (may be less if partner will cover case manager costs)

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years

H. Public Awareness. Develop a public awareness campaign. Work to change society's attitudes about hospice and palliative care, and death and dying.

Problem statement:

- The public, providers and policymakers need to understand that hospice care is not brink-of-death care.
- The public needs to understand that palliative care is not just about pain management but about symptom management broadly defined. They also need to understand that palliative care can be offered in conjunction with life-sustaining care or from the moment of receiving a terminal illness diagnosis.
- The community, in general, and providers, in particular, need to become more comfortable with death and dying and more willing to deliver, request, and cover palliative and hospice care.
- A public awareness campaign needs to:
 - Let people know they have a right to pain and symptom management; and
 - Let people know they have a hospice benefit and that it means choice, dignity and the option of care at home.

Project description and specific deliverables:

- In order to help the community in general to become more comfortable with death and dying and more willing to use palliative and hospice care, research and build on the successful track record of other programs across the country, such as the Kansas LIFE Project—Living Initiatives for End-of-Life Care.¹³ Following on the Kansas LIFE Project model, the project would:
 - Develop a public awareness campaign, with the support of the Colorado Broadcasters Association, about the issues facing Coloradans nearing the end of life.
 - Staff a toll-free consumer information helpline.
 - Use a statewide network of PBS affiliates to promote end-of-life programming.

[Note: Critical to this is the development of a consortium or partnership arrangement. (See Project A and more on Kansas LIFE Project below.)]

- The project would also:
 - Target baby boomers.
 - Develop a program that focuses on educating people under 18 years of age regarding experiences of chronic illness, loss, grief, and death. The program would acquaint them with service providers who specialize in working with each of these experiences. Education would occur through extensive collaborations with existing community groups (e.g., schools, grief groups,

¹³ For more information, see the report, "Kansas LIFE Project: The First Five Years, 1998-2002."

religious organizations, scouts, sports, etc.). The project would get on the agendas of school educators, grief groups, schools, and hospices. It would use teen volunteers, as Hospice and Palliative Care of Western Colorado does. It would also involve Girls Scouts and other similar service programs.

- Build on successful, local Rallying Points public awareness campaigns.
- Focus on resources already in place.
- Link national and our efforts (e.g., local VA efforts). The project would identify groups to access consumers (e.g. veterans' organizations).
- Include end-of-life measures in Colorado's Healthy People 2010 health indicators.
- Get media and others who are gatekeepers of education to disseminate information (example: PSA's not being run.)
- Identify community information disseminators (e.g., barbers, beauticians, deacons, etc.) and ask them to share and distribute information.
- Have a 9Health Fair education booth.
- Sponsor a statewide "Life Planning Week."

Is something similar being done here or elsewhere in the country?

- Yes, including in Grand Junction.
- The Kansas LIFE Project developed a successful public awareness campaign supported by the Kansas Association of Broadcasters. The campaign focused on the issues facing Kansans nearing the end of life. Elements included such things as an extensive community campaign entitled "Every Kansan Should Expect Good Pain Management," a campaign called "Advance Care Planning: Do It for Those You Love," and promoting a 15-part newspaper series called "Finding Our Way."

Evaluation plan (how will we know if the project was successful, made a difference?):

- Track consumer demand for information about and utilization of hospice care, palliative care, and advance medical directives before and after campaigns aimed at target groups.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization
- Local hospice(s)
- Other local association(s). Examples:
 - Alzheimer's Association
 - Colorado Cancer Coalition
 - Funeral homes
 - Churches and synagogues
- University of Colorado Health Sciences Center
- Consultant (e.g., PR consulting firm)
- Other:

Approximate number and types of paid staff needed for this project:

0.5 – 1.0 FTE to coordinate the effort and to sign up and train local organizations to participate in the public awareness campaign.

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000
- More than \$100,000

Budget estimate assumes broadcasters and others would donate air time and provide other in-kind assistance. Based on the Kansas experience, this is most likely to occur if the campaign is backed by a broad coalition of groups concerned about end-of-life issues, such as the one recommended under Project A.

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

Other comments:

There will be a need for both an initial educational effort as well as ongoing support.

I. Medical Education. Make palliative care a more substantial part of medical education.

Note: Hospice of Metro Denver recently received one year of funding under a federal grant to make palliative care a more substantial part of medical education. The project recommended in this section would extend and build on that program.

Problem statement:

Although chronic illness is the most prevalent type of illness, the academic medical centers are still attuned to training for acute and curable disease episodes. Medical education in some parts of the country has made a significant addition of palliative medicine and care to the students’ and residents’ experience recognizing the pertinence to the aging population that doctors will be treating. UCHSC has many talented palliative care and end-of-life advocates but has not achieved a systematic and meaningful exposure for most of the students and residents.

Project description and specific deliverables:

- Inventory all the current medical education opportunities available to medical students and to residents in Colorado, and the number utilizing elective rotations.
- Develop Joint Competency-based Curriculum for Family Practice and Internal Medicine Residents.
- Develop a plan to expand the amount of training exposure to didactic and field experience of hospice and palliative care. The project would address the needs of Chiefs of Medicine, Family Medicine, and Oncology.
- Develop a palliative care fellowship.
- Develop curricula for 3rd and 4th year medical students, including the culture of medicine (e.g., “Detoxifying Death”).

Is something similar being done elsewhere in the country?

Yes. For example, several years ago, The University of Pittsburgh School of Medicine received a \$750,000 grant from the National Cancer Institute to integrate end-of-life issues into the school's curriculum so that medical students could better learn how to care for dying patients and their families.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Changes instituted in curriculum.
- Student evaluations.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization. Examples:
- Local hospice(s)
- Other local association(s). Examples:
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Hospice of Metro Denver’s new End of Life Institute (some funding for this purpose is included in HMD’s federal grant)

Approximate number and types of paid staff needed for this project:

2.0 FTE: 0.7 director of medical education and faculty, 1.3 admin and training coordinator

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000

- \$50,001 - \$100,000
- More than \$100,000

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

Other comments:

We know that this project will require multi-year funding. HMD has the one-year federal grant at this point. HMD is hopeful that the Center for Medicare and Medicaid Services (CMS) will recognize the longer term need and continue funding for 2-3 years, but HMD will be looking for other sources of financial support as HMD develops this.

J. Payment. Address insurance industry and reimbursement issues, in part through pilot programs.

Problem statement:

- Although studies have demonstrated that improved pain and symptom management, caregiver support, and advance care planning can reduce costs and improve patient and family quality of life, many employers (who make benefit decisions) and health plans are unaware of the value of providing people with a quality end-of-life experience.
- Current economic incentives to keep treating patients need to be addressed.
- Funding is needed to cover the cost of training family caregivers.
- Pre-hospice palliative care services (i.e., services for people who are more than 6 months from death) are not covered by insurance.
 - To achieve long-term sustainability for programs that provide coordinated care to pre-hospice patients and their caregivers, reimbursement by third-party payers is critical.
 - Pre-hospice care services are nearly identical to currently established disease or illness management models that are providing care to patients that have demographic similarity to palliative care patients. The majority of these models receive reimbursement from health insurance providers.

- In the absence of a specific palliative care or pre-hospice benefit, providers and patients seeking reimbursement for this kind of care have to be creative in how they bill for services.
- Continuity of care and reduction or avoidance of health care costs could be better addressed if care coordination could be included as a covered benefit under health insurance policies (covering the period from the initial diagnosis of an advanced illness through the point at which a patient meets hospice criteria).

Project description and specific deliverables:

- Work with purchasers and payers to allow for broader, more flexible definitions for reimbursement and coverage purposes. The project would seek to clearly define palliation beyond relief from pain. It would describe the types of processes, methods and activities involved in palliation and the circumstances under which it should be used.
- Investigate the feasibility of doing a Medicaid pilot on earlier access to hospice and palliative care--perhaps modeled on the Kaiser special services benefit. The project would also design care coordination demonstration projects.
- Consider the development of a special chronic care or palliative care benefit worth a specific amount--say 50% coverage up to \$1,500 or \$2,500 for services and therapies not traditionally covered by a health plan but related to palliation. The benefit could be used for services defined by the patient (e.g., massage therapy, aroma therapy, social worker visits, etc.). The new benefit would be pilot tested as part of the project (similar to what Kaiser is doing).
- Establish well-defined measures of success for providers and payers to use (e.g., success measured as pain-free, conscious passing, at peace at last breath, etc.).
- Gather and write up existing research documenting the benefits of pre-hospice palliative care. The project would use this information to educate employers (e.g., Colorado Business Group on Health, CACI Business Council on Competitive Healthcare, etc.), insurance companies, Medicaid and other reimbursement agencies about the benefits of this approach to end-of-life care.
- Develop materials that explain to providers and patients the types of palliative care services that are reimbursable under most existing health insurance policies.

Is something similar being done elsewhere in the country?

Yes. For example, the Providence Health System in Portland, Oregon has a Providence Active Palliative Care (PAPC) benefit. The benefit is available to patients who are not getting better and require hospice-type services but who are still in active treatment and not yet eligible for hospice care under Medicare guidelines. The palliative care benefit is paid on a per diem basis and includes all care services, including nursing visits, pastoral care, social worker and home health aide visits.¹⁴

¹⁴ Bell K, Warren R, Sivec HD, "The Providence Active Palliative Care Benefit: An Interview with Karen Bell and Rick Warren," *Innovations in End-of-Life Care* 5 no. 4 (2003). Web site: [http:// www.edc.org/lastacts](http://www.edc.org/lastacts).

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization. Example:
 - Colorado Department of Health Care Policy and Financing (for a Medicaid demonstration)
 - Colorado Association of Health Plans
- Local hospice(s)
- Other local association(s). Examples:
 - Metro Denver End-of-Life Coalition
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Insurance Commissioner’s Office
 - Other nonprofits that focus on individual diseases that often lead to death (e.g., Alzheimer’s Association, heart association, lung association, etc.). (Each disease often has challenges particular to that disease at the end of life.)

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000—(With the exception of a pilot, most of the other components of this proposal could be broken down into specific discrete projects—developing provider materials, establishing measures of success, documenting the value of a palliative care benefit, etc.-- and funded at this level.)
- \$25,001 - \$50,000
- \$50,001 - \$100,000
- More than \$100,000 (This much money would be needed if part of this project is a pilot and/or if several components of the proposal were to be funded.)

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years (more than 3 years’ funding might be necessary if a pilot is part of this project)

K. Student training. More widely disseminate existing modules for in-school and in-the-field (on-site) end-of-life care training for students in medical, nursing, pharmacy, social work, theology/divinity and other health care schools.

Note: Hospice of Metro Denver will be using some of its recently awarded federal grant funds to target improved end-of-life training for medical students and some pharmacy students. It also plans to work with the University of Denver on its curriculum for social workers, and with Regis University and Metro.

Problem statement:

A number of excellent palliative care curricula have been developed for health professionals, including EPEC (Education for Physicians on End-of-life Care) and EPERC (End of Life/ Palliative Education Research Center packages). Yet most students in the health professions do not have any, or only very limited exposure to palliative care precepts or field experience. To meet the demands of the growing cohort of elderly and chronically ill, it would be desirable to deploy palliative care curricula more widely in various schools of health disciplines.

Project description and specific deliverables:

- Inventory and evaluate existing course and curricular offerings in palliative care at metro area schools of nursing, pharmacy, social work, divinity and theology, and for certified nursing assistants.
- Target the dissemination of key curricular topics and clinical exposure by discipline and/or school and develop plans to implement with the schools. This would involve working program by program and developing a high-level “champion” within each school to advocate for hospice and palliative care education.
- Become a resource clearinghouse to these schools for training materials, faculty, field experience, and leadership in palliative care.

Is something similar being done elsewhere in the country?

Yes. Examples include programs sponsored by the Suncoast Institute, Case Western Institute, Hospice of Michigan Institute, and locally at the Western Colorado Institute for Palliative Care.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Increased number of hours and courses in recognized palliative care curricula.
- Increased field experience in hospice/palliative care at various sites.
- Positive student evaluations.

Type of entity that might carry out the project:

— Colorado Hospice Organization

- Other statewide organization. Example:
- Local hospice(s)—(as field sites)
- Other local association(s).
- University of Colorado Health Sciences Center or medical school
- Consultant—to do inventorying)
- Other:
 - Hospice of Metro Denver’s new End-of-Life (educational) Institute
 - Other health professional schools (Regis, Iliff, DU, CSU, Mesa, etc.)

Approximate number and types of paid staff needed for this project

2.5 FTE: 1.5 experienced educators, 1 admin

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000 (This would be the cost per project if the proposal were broken down into discrete projects by school or discipline. The inventory of existing educational practices and identification of gaps could also be funded separately.)
- \$50,001 - \$100,000
- More than \$100,000 (This would be needed to fund the entire proposal.)

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- 2 – 3 years
- More than 3 years

L. Cultural Issues: Educate and develop programs to increase the level of cultural competency for people providing palliative and end-of-life care services. Develop strategies for addressing issues of access, health disparity and quality of care with diverse communities incorporating cultural knowledge. Develop standards for linguistically competent services.

Problem statement:

- Some subgroups of society have particularly low rates of hospice and palliative care utilization. This may be because they are unaware of these services, they view them as brink-of-death care, or there are language barriers. Studies indicate that this problem varies from community to community. For example, in some cases it may be more of a problem in certain rural areas, in other cases it may be more of a

problem among certain low-income populations, certain ethnic or racial groups, or certain religious communities.

- There is a need to ensure sensitivity and understanding on the part of those providing end-of-life care about how different people view end-of-life issues. Health care providers sometimes make unfounded assumptions about people's attitudes and concerns about end-of-life issues based on their race, religion, ethnicity, sexual orientation or social class. Other times they assume that most people share essentially the same concerns about end-of-life issues when this is not in fact the case. In both cases the problem is that the health care provider needs to, but too often doesn't, ask, "What are *your* issues and concerns, what's important to *you*, what are *your* goals?"

Project description and specific deliverables:

- In order to gain access to different groups that are underserved when it comes to hospice and palliative care, develop special initiatives, especially with faith-based communities. The project would research and build on proven models from other parts of the country (e.g., a successful model in South Carolina and a cancer screening model in the Latino community). It would also identify and focus on natural support systems in the community (e.g., churches, ethnic organizations, etc.).
- Inventory bilingual hospice, palliative care and end-of-life service providers and develop a major marketing effort around letting people know that there are linguistically competent service providers available who can help them with hospice and palliative care services.
- Educate and develop programs to increase the level of cultural competency for people providing palliative and end-of-life care services. The project would focus not only on ethnic and racial cultures, but also on the minority sexual culture (e.g., gay, lesbian, bisexual and transgender people.)
- Develop strategies for addressing issues of access, health disparity and quality of care with diverse communities incorporating cultural knowledge.
- Develop standards for linguistically competent services.

Is something similar being done elsewhere in the country?

Yes. Florida's Hospice by the Sea received grant funding in 2002 to support a program called "Abriendo Puertas" (Opening Doors). The program is aimed at boosting Hispanics' use of hospice care in Palm Beach and Broward Counties. Under the program:

Hispanic families who choose to care for their loved ones in their own homes will be served by hospice using three approaches to improve understanding and access to hospice services: (1) an educational outreach emphasizing

*hospice as a program, not just a place, designed to support, not replace, the family's ability to provide end-of-life care; (2) customized services, including the creation of a special, culturally responsive, bilingual interdisciplinary patient care team for Hispanic hospice patients; and (3) a cultural competency learning program to enhance the cultural sensitivity of all Hospice By The Sea staff and other community health care providers, including hospitals, nursing homes, and physician offices.*¹⁵

Chile, Argentina and Mexico have established clear standards for cultural competency.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Examine hospice and palliative care utilization rates in target areas before and after program intervention.
- Evaluate comfort with and knowledge of hospice and palliative care services in the target communities.

Type of entity that might carry out the project:

- Colorado Hospice Organization (but needs to be done in collaboration with an organization(s) representing different minority groups)
- Other statewide organization. Examples:
 - Minority Health Forum
 - The Gay, Lesbian, Bisexual, and Transgender Community Center of Colorado
 - LARASA
 - Colorado Consumer Health Initiative
- Local hospice(s) (but needs to be done in collaboration with an organization(s) representing diverse groups)
- Other local association(s). Examples:
 - Metro Denver Black Church Initiative
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Clinics and physician practices
 - UC Denver

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000—(Not including an expensive, major marketing campaign.)
- \$50,001 - \$100,000
- More than \$100,000

¹⁵ "Hispanic Influence Grows, But Not in Hospice Care: FL Hospice Offers Special Outreach," December 2002. Web site: http://www.findarticles.com/cf_dls/m0KGZ/12_7/95527529/p1/article.jhtml.

Length of time needed to complete the project:

- Up to 6 months
- 6 months – 1 year
- 1 – 2 years
- More than 3 years

M. Field Education. Increase capacity for hospices and palliative care centers to provide field education to students—oversight, supervision, and training the trainers.

Note: Hospice of Metro Denver will use some of its recently awarded federal funds to expand hospice rotations for students in the metro Denver area. Hospice and Palliative Care of Western Colorado is already doing this in the Grand Junction area.

Problem statement:

Hospices generally have limited internal staff available for coordinating and training students and for training and supporting the nurses, social workers, and chaplains who provide valuable clinical experience to health care students. Yet more clinical exposure in homecare, assisted living, nursing home, and care center settings is invaluable to students to gain the true picture of palliative care in family dynamics, symptom management, clarifying goals of care, etc. Expanding the capacity of hospices and other pertinent settings to provide this experience would improve palliative education.

Project description and specific deliverables:

- Develop/expand on-site hospice rotations with:
 - Iliff School of Theology;
 - DU/CSU School of Social Work;
 - CU, Regis, Metro Schools of Nursing; and
 - Outstate schools like Mesa
- Provide hospices with student-specific curricula.

Is something similar being done here or elsewhere in the country?

Yes. As noted above, Hospice of Metro Denver is initiating a program in the Denver metro area and Hospice and Palliative Care of Western Colorado has a program in Grand Junction. The Suncoast Institute in Florida, Buffalo NY Institute, and San Diego Hospice Institute have sponsored similar programs.

Evaluation plan (how will we know if the project was successful, made a difference?):

- Measure the number and types of clinical rotations in place with various schools.
- Student evaluations.

Type of entity that might carry out the project:

- Colorado Hospice Organization
- Other statewide organization. Examples:
 - Hospice Alliance of Colorado
- Local hospice(s)
- Other local association(s).
- University of Colorado Health Sciences Center or medical school
- Consultant
- Other:
 - Hospice of Metro Denver's new End of Life Institute¹⁶

Approximate number and types of paid staff needed for this project:

2.5 FTEs (1.5 clinical trainers and 1.0 administrative person).

Ballpark project cost estimate per year and budget assumptions:

- Under \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$100,000
- More than \$100,000

Incremental progress can be attained sooner and for less than \$100,000, but to truly develop an interdisciplinary training network will require persistence and resources.

Length of time needed to complete the project:

- 1 – 2 years

¹⁶ Funds for this purpose are included in Year 2 of HMD's federal grant.

Sustaining the Collaboration

In addition to developing a recommended list of proposals, the Planning Committee was asked to begin the process of developing a “genuinely collaborative, inclusive and self-sustaining process that allows those concerned about palliative and end-of-life care to work together on issues of mutual concern on an ongoing basis.” The group came to consensus on several elements of that process:

- **As recommended under project proposal A, an independent, statewide partnership organization should be established.** It should be set up along the lines of the Kansas LIFE Project and dedicated to improving access to quality end-of-life care in Colorado and fostering cooperative working relationships among those involved in hospice and palliative care.
- **The collaboration should include the types of partners involved in the Kansas Life Project** (e.g., governmental agencies, academic institutions, minority groups, consumer groups, cities and counties, media organizations, medical providers, pain control facilities, professional organizations, foundations, the VA Hospital and others).
- **The new organization should use the list of projects presented in this report** as the core of its strategic plan of action.

The Colorado Hospice Organization recently indicated its intent to form a new partnership organization. It intends to work with interested members of the Planning Committee as well as other interested groups to form this new organization and secure seed money.

For More Information

For more information, contact:

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Appendix

Glossary of Terms^a

Advance medical directive. An advance medical directive (also known as a living will) is a document in which an individual sets forth his or her wishes in case of terminal illness or persistent unconsciousness where the individual is no longer capable of participating in his or her health care decisions. This document contains the instructions regarding a care recipient's wishes and desires for health care, including what treatment is not desired, such as a Do Not Resuscitate/DNR order.

Cultural competence. "Culture" refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups. "Competence" implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities

Disease management. A coordinated care approach focused on prevention, early identification, and intervention in the chronic disease process. By controlling factors that determine the early course of a chronic condition, disease management proponents attempt to show that such programs improve individual health status, control medical costs, and reduce the incidence of work limiting disability.

Hospice care. Hospice care is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments. Hospice care neither prolongs life nor hastens death. Hospice addresses all symptoms of a disease, with a special emphasis on controlling a patient's pain and discomfort. The goal of hospice care is to improve the quality of a patient's last days by offering comfort and dignity. Hospice deals with the emotional, social and spiritual impact of the disease on the patient and the patient's family and friends. Care is provided by a team-oriented group of specially trained professionals, volunteers and family members.

Living will. (See "advance medical directive.")

Palliation. (See "palliative care.")

Palliative care. Palliative care (also known as palliation) is intended to soothe or relieve the symptoms of a disease or disorder without effecting a cure. It involves active, interdisciplinary comfort care, and focuses both on aggressive control of the patient's pain and other physical symptoms and on the emotional, social and spiritual priorities of the patient and family.

Quality dying experience. As used in this report, a quality dying experience means facing death with unimpeded, convenient access to appropriate, patient-directed end-of-life care and culturally appropriate services that address the patient's spiritual, physical, emotional and practical needs.

^a Sources: The Carolinas Center for Hospice and End of Life Care; Hospice Foundation of America; "Legal Issues for LGBT Caregivers," Family Caregiver Alliance; and Massachusetts League of Community Health Centers.