

Feasibility Study Concerning The Creation of a Colorado Center for End-of-Life and Palliative Care

Prepared for:

Bonfils-Stanton Foundation

Rose Community Foundation

Final Report

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Executive Summary

Feasibility Study Concerning the Creation of a Colorado Center for End-of-Life and Palliative Care

Bonfils-Stanton Foundation and Rose Community Foundation contracted with Yondorf & Associates in September 2002 to look into the need for, and possible ways to structure, a Colorado center for end-of-life and palliative care. The feasibility study was prompted by a funding request from the Center for Bioethics and Humanities at the University of Colorado Health Sciences Center to create an end-of-life center.

The feasibility study examines the need for a center, the types of activities a center might undertake, who the audience(s) for a center would be, the relationship of a new center to already-established programs, center funding and staffing, and lessons from other states. It is based on in-depth interviews/surveys of 47 people in Colorado who are involved in hospice and palliative care or represent patients and families concerned about end-of-life care ("Colorado interviewees"); an examination of seven centers in other states; interviews with several center directors; a literature review; and a review of related programs in Colorado.

The study found that most Colorado interviewees believe there is a need for some kind of Colorado center for end-of-life and palliative care if it is structured properly. However different people had different notions about what the primary function of a center should be. Nonetheless, Colorado interviewees did agree that if a center is established it should be a genuinely collaborative endeavor, have a statewide rather than just a Denver focus, be practical, and not threaten funding for existing programs. It should also have a stable home and funding base, and a long-term plan for sustainability.

In terms of Colorado's end-of-life care system as a whole, Colorado interviewees said that the most important needs are: patient, family and public education; training of medical professionals and students; improved reimbursement; loosening stringent regulations; improved community collaboration; enhanced support for caregivers; and improved access to care. At the same time, the study found that there are already a number of organizations in Colorado and around the country working on these issues.

The main finding of the feasibility study is that there is no central coordination of existing efforts and, in many cases, people are not aware of who is doing what or where to go for help. Also, there is no locus of responsibility for filling gaps in the system or monitoring and improving the system as a whole.

The study found no clear consensus among Colorado interviewees about where to locate a Colorado center. Some said at the University of Colorado Health Sciences Center in the Center for Bioethics and Humanities. Hospice directors favored the Colorado Hospice Organization. Others said in a freestanding nonprofit or elsewhere. Whatever their preference, most people agreed that if a center is established it should be organized as a co-equal partnership between the community and the University.

The major recommendation stemming from the feasibility study findings is that a phased approach to the possible creation of a center should be adopted. This is because it is not

clear whether or not an actual formal center is needed, and setting one up involves a substantial financial commitment. The first two steps in a phased process should be to:

- 1) Convene interested parties to identify ways in which, with modest additional funding, they could expand on their current activities to address system needs, and identify those needs that cannot be met through existing programs, and
- 2) Consider funding a coordinating/clearinghouse position. This may go a long way toward solving some of the most important unmet needs in the system. Also, it may be that by housing such a position in an organization that already has the capacity to carry out many of the roles of a center, a *de facto* center will be the result. This latter outcome is especially likely if linkages among existing programs can be formalized.

It is also recommended that, whatever is done, it should be the result of a genuinely collaborative process that is focused on making maximum use of existing resources and that has long-term sustainability.

The major findings and recommendations of the feasibility study are shown in the table that begins on the next page.

Major Findings and Recommendations

Colorado Center for End-of-Life and Palliative Care Feasibility Study

Prepared for Bonfils-Stanton Foundation and Rose Community Foundation

Findings	Recommendations
I. Systemwide Needs Assessment	
<ul style="list-style-type: none">• According to Colorado interviewees, the most critical needs in Colorado's end-of-life system are: community education; training of medical professionals and students; improved reimbursement; loosening stringent regulations; improved community collaboration; support for families/caregivers; and improved access to care.• Colorado interviewees had different ideas about how best to meet these needs. Suggestions include creating some type of center, funding a public awareness campaign, underwriting training for health professionals, supporting research and demonstration projects, and providing more funding for existing hospice and palliative care programs.	<ul style="list-style-type: none">• The main focus of efforts to improve Colorado's end-of-life and palliative care system should be on community education, training health professionals, making it easier for patients to access and afford care, support for families and caregivers, and improved community collaboration.• The best way to meet systemwide needs may be by creating some kind of center or it may be by simply expanding current efforts, particularly in the areas of community education, training, research, and hospice and palliative care.
II. The Need for a Colorado Center for End-of-Life and Palliative Care	
<ul style="list-style-type: none">• Most of the Colorado people interviewed for this study believe there is a need for some kind of Colorado center, but only if it is structured properly. Interviewees said a Colorado center needs to be practical, serve the entire state and not just Denver, be a genuinely collaborative endeavor, and not threaten funding for existing programs.• Proponents said that a Colorado center is needed because: a coordinated effort is required to change the system; Colorado needs a central resource center; and leadership is needed to address growing end-of-life and palliative care problems associated with an aging population.• The most important need centers in other parts of the country say they are meeting is to serve as a source for practical information and assistance.	<ul style="list-style-type: none">• It appears that, at minimum, there is a need for some kind of statewide coordinating/clearinghouse function. Colorado needs a central, statewide source for practical information, assistance, and referrals that serves both health care professionals and the public, and that coordinates existing efforts in the state.• Whether or not a formal center is needed is not clear. There are several less expensive alternatives that might be able to meet the same needs that supporters of a center see it meeting. What is clear is that whatever is done should be the result of a collaborative process focused on maximizing the use of existing local and national resources.

Findings	Recommendations (p. 2)
III. Activities of a Colorado Center	
<ul style="list-style-type: none"> Colorado interviewees said if a center is set up, its most important activities should be to improve and enhance training of health professionals, and facilitate collaborative projects at the community level. Other priorities include research on financing, reimbursement and improved models of care, and assisting the public and providers to link up with appropriate resources. The major activities that centers in other states engage in are to: train health care professionals; sponsor community education programs; produce educational materials; conduct research; develop curricula; engage in community collaboratives; provide technical support; and serve as a resource center. 	<ul style="list-style-type: none"> If a Colorado center is established its initial priorities should be those identified by Colorado interviewees. They include: working for more and better training of health professionals; facilitating community collaborative projects, in part by building on the work of The Colorado Trust Palliative Care Initiative; encouraging research on financing, reimbursement and improved models of care; and assisting the public and providers to link up with appropriate resources.
IV. Existing Resources	
<ul style="list-style-type: none"> Colorado already has a number of excellent programs in place that are engaged in training, public education, research, advocacy, technical assistance, collaborative community projects, and patient/family support. <u>However</u>, there is no central coordination of these efforts and, in many cases, people are not aware of who is doing what or where to go for help. Also, there is no locus of responsibility for filling gaps in the system or monitoring and improving Colorado's end-of-life system as a whole. Colorado interviewees said that if a Colorado center is set up, its role in relation to already existing programs should be to coordinate and enhance their efforts. The Colorado Hospice Organization (CHO) is the most frequently cited source for assistance on end-of-life and palliative care questions by Colorado interviewees. 	<ul style="list-style-type: none"> 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.

(continued on the next page)

Findings	Recommendations (p. 3)
V. The Audience for a Colorado Center	
<ul style="list-style-type: none"> Colorado interviewees said the primary audiences for a Colorado center should be: physicians, nurses and social workers; academic medical/health programs; the general public; and hospitals and hospices. The four primary audiences for centers in other states are: practicing community health care professionals; academic medical/health programs; those interested in end-of-life research; and health care institutions. 	<ul style="list-style-type: none"> The major audiences for a Colorado center or coordinating/clearinghouse entity should be practicing community health professionals, academic medical/health programs, the general public, and health care institutions.
VI. Level of Funding Needed to Establish a Colorado Center	
<ul style="list-style-type: none"> Estimates of the amount of money needed to start a center range from \$100,000 to \$600,000 for the first year. The centers in other states that were examined for this study have annual budgets ranging from \$200,000 (for one of the newest centers) to \$3.2 million. Research grants and foundation support are the major sources of outside funding for end-of-life and palliative care centers. Center directors in other states and several Colorado interviewees said sustainability of a Colorado center is a major issue. 	<ul style="list-style-type: none"> Given the large sums required to start up and sustain a center and the reality of limited resources, it is recommended that a phased approach be adopted. The first two steps should be to: <ul style="list-style-type: none"> Convene interested parties to identify ways in which, with modest additional funding, they could expand on their current activities to address system needs, and identify those needs that cannot be met through existing programs. Consider funding a coordinating/clearinghouse position. This may go a long way toward solving some of the most important unmet needs in the system. Also, it may be that by housing such a position in an organization that already has the capacity to carry out many of the roles of a center, a <i>de facto</i> center will be the result. This latter outcome is especially likely if linkages among existing programs can be formalized.

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Findings	Recommendations (p. 4)
VII. Establishing a Colorado Center: Organizational Issues	
<ul style="list-style-type: none"> • There is no consensus about where to locate a Colorado center. Some think it should be at the University of Colorado Health Sciences Center (UCHSC) in the Center for Bioethics and Humanities. Others (mainly hospice directors) think it should be administered by the Colorado Hospice Organization (CHO). Still others want it housed in a freestanding nonprofit or in some other location. • A number of people who selected a location other than UCHSC either strongly opposed locating a Colorado center there or expressed serious reservations. • For many people, the preferred model is some sort of co-equal partnership between the community and the University. • Experienced center directors and Colorado interviewees said that the executive director of a center should have a track record of success in building programs and a passionate interest in the subject, and should be a great collaborator. 	<ul style="list-style-type: none"> • If a center or coordinating/clearinghouse position is established, it should be established where it can make maximum use of existing organizational resources. Ideally this would be in an organization that is already widely used, and generally considered to be an accessible, responsive and reliable source of end-of-life information. • Location of a center or coordinating/clearinghouse function should be decided through a consensus process that involves the major interested parties. • The people involved in a center or coordinating/clearinghouse function should have strong end-of-life and palliative care experience, and good facilitation and collaboration skills. • If a formal center is established, it should be modeled on the partnership arrangement between the University of South Florida and The Hospice of the Florida Suncoast. (For more information on this arrangement, see "Advice from Other States" in Chapter VII.)
VIII. Additional Lessons From Other States and Observations by Colorado Interviewees	
<ul style="list-style-type: none"> • Directors of centers in other states noted the importance of building partnerships, doing a needs assessment prior to setting up a center, and being clear about the center's mission and focus. • Several Colorado interviewees said they thought the overarching objective of the center should be to transform the medical system. They also talked about the role of an informed, energized public in spurring physicians to become better educated about end-of-life and palliative care; the need to pay attention to the palliative care needs of people with progressive, disabling conditions; and the importance of cultural competency in end-of-life care. • Based on their experience with past Colorado efforts, Colorado interviewees recommended that if a Colorado center is created, it should be collaborative, inclusive, and diverse; have a stable home and funding base; and be action-oriented. 	<ul style="list-style-type: none"> • Because it is clear that those involved in and concerned about end-of-life care in Colorado have strong feelings about the direction and activities of a Colorado center, any planning activities related to the development of a center or related projects should be allowed to proceed slowly and deliberately. It is critical that whatever time is needed should be taken to allow for the development of trust and respect among interested parties and for reaching true consensus as to how to proceed with mutually agreed upon goals. This is necessary in order to develop a cost-effective plan of action that has broad community support.

Introduction

Purpose and Background

This report examines the need for and possible ways to structure a Colorado center for end-of-life and palliative care¹ that would work with communities and health professionals across the state to improve end-of-life care. There are at least 13 centers around the country dedicated to research, training and/or community collaboratives focused on end-of-life and palliative care issues. (See Appendix A.) Colorado does not currently have such a center, although various shops throughout the state, in limited ways, provide some of the functions of a center.

In March 2002, the Center for Bioethics and Humanities at the University of Colorado Health Sciences Center (UCHSC) submitted a grant request to Rose Community Foundation to fund the initial planning for and development of a Center for End-of-Life and Palliative Care. According to the grant request, the center would “foster education and collaboration to improve end-of-life and palliative care throughout the metro area and the state,” and “focus on and influence how best to increase the provision of effective, reliable and compassionate end-of-life care.” One of the main goals of the center would be “to generate substantive improvements in health care, community life, and personal well-being by improving current practice in the area of death and dying and inspiring new approaches.”

Rose Community Foundation reviewed the UCHSC request and concluded that it did not have sufficient information to award a grant. The Foundation decided that before committing funds to such a venture, it wanted an independent assessment of the need for a center for end-of-life and palliative care in Colorado. Bonfils-Stanton Foundation also indicated a similar interest. In September 2002, the two foundations contracted with Yondorf & Associates, a Denver-based health policy consulting firm, to conduct the independent assessment.

The contract called for Yondorf & Associates to research eight questions, each of which is briefly described in Table 1. The research questions concern the need for a center, the types of activities a center might undertake, who the audience(s) for a center would be, the relationship of a new center to already established programs, center funding and staffing, and lessons from other states.

Chapters I through VIII of the report discuss findings with respect to each of the eight research questions. Each chapter begins with a summary of major findings and ends with recommendations. A complete list of findings and recommendations from all the chapters is presented in the table that accompanies the Executive Summary.

Information Sources

Yondorf & Associates relied on five main information sources in conducting the feasibility study:

- Interviews with and surveys of 47 people in Colorado who are involved in hospice and palliative care or represent patients and families concerned about end-of-life care

¹ “Palliative care” 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.

Table 1

Feasibility Study Questions

1. What are Colorado's priority needs with respect to establishing and maintaining a high quality end-of-life and palliative care system?

Where are the major shortcomings of the existing system? Do they have to do with access to care, lack of training, lack of information by patients and caregivers about their options, or something else? What's the best way to meet these needs?

2. Is there a need for a Center for End-of-Life and Palliative Care in Colorado?

What is it that is not currently being done that could best be addressed by establishing a Colorado center? What important difference would a center make? Who would benefit in what ways from the creation of a center?

3. What kinds of activities might a Colorado center undertake?

Should it train health professionals, provide technical support to existing palliative and hospice care programs, or serve as a resource center for patients, families and community groups? Should it focus on research, ethical issues, advocacy, or disseminating information about best practices?

4. Who should be the primary audience(s) for the center's work?

Should the primary audience be health professionals in training (e.g., medical, nursing and pharmacy students), practicing providers in the community, or patients and families? Should policymakers, the general public, or the media be primary audiences? What about hospitals, nursing homes, and hospices?

5. What would be the role of the center vis-à-vis other already established centers and groups dealing with end-of-life and palliative care issues?

What should be the relationship between a new center and the variety of different groups in Colorado and around the country involved in training, community education, outreach, and research with respect to end-of-life and palliative care?

6. What level of funding would be required to start up and sustain a Colorado End-of-Life and Palliative Care Center?

What are start-up costs for a center? What kind of ongoing operating budget would a center require? Is it likely that a Colorado center would be sustainable over the long run? What are possible funding sources?

7. Where should the center be housed and how should it be organized?

Should the center be established as part of the University of Colorado Health Sciences Center? Should it be established as a freestanding, nonprofit entity or in conjunction with an existing hospice program? What are appropriate staffing levels and what kinds of people should be hired to staff the center? What about governance of the center?

8. What additional lessons can be learned from the experience of centers in other states and observations of knowledgeable people in Colorado?

What have been the keys to success for centers in other states? What advice do center directors have for Colorado? What additional advice do knowledgeable people in Colorado have? What lessons can be learned from previous efforts in Colorado?

("Colorado interviewees"). The 47 interviewees accounted for 38 total respondents, since some people were interviewed as a group.² (See Table 2 for a list of interviewees and survey respondents by type of respondent. See Appendix B for the names and affiliations of those interviewed, and Appendix C for a copy of the questionnaire used in the interviews and the written survey.)

- Research into existing programs and groups in Colorado already engaged in education, training, research, technical assistance and/or outreach with respect to end-of-life and palliative care.
- A review of available published information on seven sample end-of-life and palliative care centers that represent different organizational approaches to forming a center. (See Table 3 for a list of the seven centers. See Appendix D for detailed charts describing the history, organization, funding, staffing and boards of directors of the seven state programs.)
- Interviews with the directors of four centers in other states. (See Table 3 for the centers whose directors were interviewed. See Appendix B, part 4 for the names of the four center directors.)
- A literature review.

Acknowledgments

This report would not have been possible without the cooperation of the more than 50 people in Colorado who are involved in hospice and palliative care or represent patients and families concerned about end-of-life care who took time from their busy schedules to assist with this project. Some sat down with feasibility study staff to share their thoughts about the possible creation of a Colorado center for end-of-life and palliative care. Others contributed data or background information. Their names and affiliations are shown in Appendix B.

The four directors of programs in other states who agreed to be interviewed for this study offered invaluable insights into the promises and potential pitfalls of a center for end-of-life and palliative care and gave generously of their time. Program staff at other centers also were helpful in assisting Yondorf & Associates to put together the center charts shown in Appendix D. For a list of people from other states who assisted with this project, see Appendix B.

Thanks to you all.

² Surveys were sent to all 36 of Colorado's hospice directors and the executive director of Colorado Hospice Organization; 18 returned surveys.

Table 2			
Colorado Interviewees and Survey Respondents by Type Of Respondent			
Type and Number of People Interviewed or Surveyed *			
Consumer group representatives	16	Black, Non-Hispanic	9
Hospice directors	18	Hispanic	2
Other knowledgeable people	13	Other	36
TOTAL	47	TOTAL	47
Physician	5	University-based person	5
Nurse	17	Clergy person	5
Ethicist	1	Social worker	4
Other	24	Attorney	2
TOTAL	47	Nursing home administrator	1
Denver metro area	37	Pubic policymaker	1
Non-Denver metro area (primarily rural)	10	Other	29
TOTAL	47	TOTAL	47
<p><i>* In all, 47 Coloradans were interviewed or filled out a written survey for the study. However, several of these people participated in group interviews. (See Appendix B for more detailed information about individual and group interviewees.) Because group interviewees were not polled separately, the input of everyone attending a particular group interview is counted as a single response throughout the report. Thus, the 47 people who participated in the study account for a total of 38 responses.</i></p>			

Table 3	
End-of-Life and Palliative Care Centers Included in the Study	
Center	Location
The Center for Excellence in End-of-Life Education, Research and Practice	Cheektowaga, New York (Buffalo area)
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida *	Tampa, Florida
The Center for Palliative Care Studies at San Diego Hospice*	San Diego, California
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY	New York City, New York
The Hospice Institute of the Florida Suncoast *	Largo, Florida (Tampa-St. Petersburg area)
Maggie Allesee Center for Quality of Life, Hospice of Michigan	Detroit, Michigan
Midwest Bioethics Center *	Kansas City, Missouri
<p><i>* Conducted in-depth interview with executive director and/or senior staff.</i></p>	

I. Setting the Context: Systemwide Needs Assessment

Major Findings

- ✓ According to Colorado interviewees, the most critical needs in Colorado's end-of-life system are: patient, family and public education; training of medical professionals and students; improved reimbursement; loosening stringent regulations; improved community collaboration; enhanced support for families and caregivers; and improved access to care.
- ✓ The systemwide needs identified in this report are largely consistent with those identified in other recent studies on the subject.

Introduction

Before launching into an examination of the need specifically for a center for end-of-life and palliative care in Colorado, Yondorf & Associates first took a broader look at the needs of Colorado's end-of-life system as a whole. The purpose of this examination was to determine whether projects other than the creation of a center might be a higher priority for those engaged in or requiring end-of-life or palliative care.

Yondorf & Associates undertook three major activities to do an end-of-life care systemwide needs assessment. First, project staff asked the knowledgeable Coloradans who were surveyed for this study the following question: "What do you see as the three most critical needs with respect to establishing and maintaining a high quality end-of-life system in Colorado and advancing the hospice concept of care?" Second, interviewees were asked, "If you were providing advice to a health care foundation interested in end-of-life care, what would you tell them is the best way to meet current needs?" Third, staff examined several recently published studies concerning areas of end-of-life care in Colorado needing improvement. The results of these efforts are discussed below.

Colorado Interviewee Needs Assessment

Colorado interviewees identified the following as the most critical needs of Colorado's end-of-life system: better education and training; improved reimbursement; less stringent regulations; improved community collaboration; enhanced support for families and caregivers; and improved access to care. (See Table 4 on the next page.)

Education and training

Consumer group representatives, hospice directors, and other knowledgeable Colorado individuals who were interviewed for this study were all in agreement about the highest priority for Colorado's end-of-life care system—namely training and education. Twenty-eight

Table 4		
Needs Assessment Regarding End-of-Life Care in Colorado-- Survey of Colorado Interviewees		
Survey Question: "What do you see as the three most critical needs with respect to establishing and maintaining a high quality end-of-life care system in Colorado and advancing the hospice concept of care?"		
Rank	No. Who Rated as Critical Need ^a	Critical Needs ^b
1.	28	Educating patients, families and the public.
2.	17	Training on end-of-life and palliative care for all medical professionals.
3.	15	Training medical students and practicing physicians.
4.	9	Getting reimbursement for palliative care, pre-hospice care, palliative care consults, etc.
5.	6	Loosening stringent rules about when hospice care is appropriate.
	6	Improving community collaboration.
	6	Getting more support for families and caregivers.
6.	4	Improving access to care and funding for care.
7.	3	Establishing a coordinating entity.
8.	3	Changing attitudes and the culture around death and dying.
9.	2	Educating community care giving professionals (e.g., chaplains, social workers, home health aides, etc.).
	2	Research.
^a Multiple responses permitted.		
^b Only lists critical needs mentioned by two or more interviewees.		

Colorado interviewees (74% of respondents) cited greater public, patient and caregiver education about end-of-life and palliative care as a top priority. Interviewees said more needs to be done to educate people about pain management, end-of-life care resources and options, advanced care planning, and patient choice. A physician who works for a large Colorado health care system said, "There is poor awareness in the community about the benefits of palliative and hospice care. People are fearful that care will be compromised rather than helped." A person from the Western Slope said, "We need to help families understand what end-of-life care means—that it means giving people excellent quality of life."

There was also general agreement among Colorado interviewees that better education of health care professionals—both those in training and practicing professionals—is a critical need. Interviewees felt that health care providers need a better understanding of what hospice and

palliative care are, when it's appropriate to refer patients to, or consult with, other palliative care experts, and how they can better serve patients and families. Several interviewees said that medical professionals need to become more comfortable with death and dying. A hospice administrator recommended, "better training of physicians to be more understanding of the medical and psychological needs of the client and significant other or caretaker."

Several people emphasized that training locally is what is needed. Almost every rural person interviewed underscored the importance of bringing training opportunities to local providers rather than making them go to Denver or out-of-state for training. This is important both because of very limited resources locally to cover travel and lodging, and because it is very difficult for rural providers to get away from their practices.

Better reimbursement and less stringent rules

Not surprisingly, improved reimbursement was a priority concern for a number of hospice directors, as was loosening stringent regulations concerning the appropriateness of hospice care. Directors were interested in getting reimbursement for palliative care consults and higher payments for hospice care. One hospice director called for more consistent funding for pre-hospice palliative care.

Another frequently cited concern was overly restrictive regulations about when a patient is eligible for hospice care under his/her care plan. One person recommended changing the six-month prognosis requirement for entry to hospice care. Another noted the problem of patients who fall between the regulatory cracks—for example, patients with a terminal illness who want or need chemotherapy but can't get hospice care if they are on chemotherapy.

Improved community collaboration

Several interviewees said improved collaboration is a critical need. One person called for more collaboration and less competition among providers. Another said there's a need for all the entities at the local level to "pull in the same direction." A third said, "We need to involve community leaders, providers in the community, family resource centers, and the public to ensure the stability and availability of good end-of-life and palliative care in the community."

More support for families, caregivers

Consumer group representatives were particularly concerned about the need for more support for families and other caregivers. A pastor listed the following as the types of support that caregivers need:

- Spiritual;
- Answering questions;
- Knowing what systems are in place to help;
- Having a mentor or contact person to rely on; and
- Providing funding to allow family members from other parts of the country to come and help out.

One person who works for an organization devoted to people with a particular chronic, disabling condition said, "People muddle along not knowing what their options are. Some families don't ask for help until it's too late." A Denver nurse noted that if family caregivers aren't given more support, "They're going to get burned out and some will die before the patient does."

Improved access

Improved access to and funding for hospice and palliative care were a priority need identified by several people. A rural hospice director recommended more funding to provide care “so [indigent care] is not a 100% loss to a small nonprofit agency.” Another said, “We need to assure broad access to hospice and palliative care in rural areas, for persons who have unknown prognoses, for children, and for Medicaid patients who require residential hospice care.” A priority for one social worker was access for undocumented patients.

Colorado Interviewee Recommended Projects

Having identified priority needs for Colorado’s end-of-life care system, Colorado interviewees were asked how those needs could best be met. Twenty-one percent of respondents said by establishing some sort of center. Fund a public awareness campaign, underwrite training for health professionals, and support research and demonstration projects were each recommended by 18% of respondents. Thirteen percent said provide more funding for existing programs. (See Table 5 on the next page.)

Establish a center

Eight of 38 respondents (21%) recommended establishing a center as the best way to address the needs of Colorado’s end-of-life care system, although people had different ideas about what the main function of the center should be. Nonetheless, most saw its main function as serving as a coordinating entity and clearinghouse. For example, one person said the center should coordinate resources, a second said it should sponsor a hotline, and a third said it should serve as a general community resource. Other suggestions for the primary function of a center were to do community education, and provide training and informational resources for medical professionals.

Fund a public awareness campaign

Seven respondents recommended community education and/or public awareness campaigns as the best way to meet identified needs. A rural provider suggested that funds should be devoted to community outreach, workshops and symposia in different venues across the state. A hospice director recommended a marketing and advertising campaign “geared on the general community acceptance of end-of-life care as a nonthreatening subject.

It is perhaps interesting to note that consumer group representatives did not rate a broad community education project as a high priority. Instead, with respect to education, they were more likely to suggest an effort targeted to patients and families or better training of health professionals.

Underwrite training of medical professionals

Survey respondents recommended funding training for medical professionals as frequently as they did funding a public awareness campaign. Someone who works with a number of Hispanic patients recommended funding programs not only for physicians and nurses but also for home health workers and others who work with the dying. She said the focus of these programs should be on getting health professionals to be comfortable with death and dying and accepting dying as a part of life. Other people noted the importance of better training for pharmacists.

<p style="text-align: center;">Table 5</p> <p style="text-align: center;">Best Ways to Meet Identified Needs-- Colorado Interviewee Opinions</p> <p style="text-align: center;">Survey Question: "If you were providing advice to a health care foundation interested in end-of-life care, what would you tell them is the best way to meet current needs?"</p>		
Rank	No. Who Recommended as Priority ^a	Best Way to Meet Needs ^d
1.	8 (21%)	Establish some kind of center. ^c
2.	7 (18%)	Fund community-wide education, public awareness campaign.
	7 (18%)	Underwrite training and continuing education programs for all types of health care professionals.
	7 (18%)	Support research and demonstration projects.
3.	5 (13%)	Provide more funding for existing hospice programs, the Colorado Hospice Organization, and other established programs.
4.	3 (8%)	Support educational programs for patients and families.
	3 (8%)	Fund training programs for medical students and physicians.
	3 (8%)	Support the development and dissemination of basic standards of care and best practices.
	3 (8%)	Provide funds to pay for speakers, training and technical assistance in rural areas.
5.	2 (5%)	Fund advocacy efforts to improve reimbursement and modify hospice rules.
<p>^a Some interviewees gave more than one response. Thus totals add to more than 100%.</p> <p>^b Only lists activities recommended by two or more people.</p> <p>^c Different respondents suggested different kinds of centers. Suggestions included a center that would coordinate resources, a center that would sponsor a hotline, a center that would do community education, a center that would provide training and informational resources for medical professionals, and a center that would serve as a general community resource.</p>		

Support research and demonstration projects

Support for research and demonstration projects was another option that was suggested by a significant number of interviewees. Examples of suggested projects included:

- Identify the number and location of people needing life transition services;
- Fund a demonstration program that provides hospice and palliative care life services to patients who have more than a 6-month prognosis to demonstrate decreased costs and increased family awareness of end-of-life issues;

- Fund research programs that advance the state of the art of end-of-life and palliative care;
- Document data on the benefits of palliative care; and
- Do a study to determine why it is that people don't use hospice and palliative care services earlier, why more people aren't taking advantage of the existing system.

Several people emphasized the importance of including minority populations in research studies.

Provide more funding for existing programs

Hospice directors were more likely than other interviewees to recommend increased funding for existing programs. Several noted that a number of hospices in Colorado are strapped for cash and hoped that local foundations would help out by providing funding for basic operating expenses. An experienced provider who has worked with programs across the state said, "The foundations should fund ongoing, substantial clinical and administrative support for current efforts." She went on to say, "The piecemeal [funding] thing is crazy-making. Little, three-year grants are not the answer."

Major Published Studies

Yondorf & Associates looked at two major studies of unmet needs in Colorado's end-of-life care system. The first one, "The Status of End-of-Life Care in Health Care Facilities in Colorado: A Survey of Hospitals, Nursing Homes and Hospices From Across the State," was published in October 1999.³ The second, "Means to a Better End: A Report on Dying in America Today," was issued in November 2002 by Last Acts, a national coalition to improve care and caring near the end of life.⁴ The findings from these two studies are briefly discussed in the sections below.

It should be noted that these are not the only studies that have been done by groups interested in end-of-life care in Colorado. However, they are among the largest and broadest of such studies. An independent group with no direct involvement in the issue conducted the first study, while the second used objective indicators to assess shortcomings in the end-of-life care system.

"The Status of End-of-Life Care in Health Care Facilities in Colorado"

The purpose of this study was "to assess the current quality of end-of-life care and palliative care, the resources currently existing in health care facilities to help health care providers, patients and their families with end-of-life care, and ways to improve the care for dying patients."⁵ The results presented in the study are based on responses to a written survey that was returned by 32 hospitals, 100 nursing homes, and 32 hospices in Colorado, for a total of 164 responses.

Some of the report's key findings, as they relate to needs within Colorado's end-of-life and palliative care system, were as follows [emphasis added]:

³ "The Status of End-of-Life Care in Health Facilities in Colorado: A Survey of Hospitals, Nursing Homes and Hospices From Across the State," National Research Center, Inc., and Center for Research Strategies, October 1999.

⁴ "Means to a Better End: A Report on Dying in American Today," Last Acts, November 2002.

⁵ "The Status of End-of-Life Care," p. 1.

- Survey respondents felt that professional training, community education and financial reimbursement were the three top areas believed to have the most potential for improving care for dying patients in institutions across the state. Other areas included emphasis on advanced planning, research on patient preferences, legislation, liaison among facilities, and research on prognosis of death.
- All respondent groups reported that reluctance to stop aggressive treatment was the key barrier to physician referrals to hospice, followed closely by reluctance to discuss end of life issue with patients. Similar barriers were felt to discourage patient use of hospices. A lack of knowledge about hospice was also felt to be a major deterrent to timely hospice referral.
- Hospitals and nursing home administrators acknowledge that they are not meeting the needs of dying patients as well as they could. Attention to spiritual needs and inter-disciplinary coordination with palliative specialists were the areas rated as least adequate by administrators. Respondents also saw a need to work on improved pain management.

“Means to a Better End: A Report on Dying in America Today”—Colorado Report Card

The Last Acts coalition examined a variety of indicators about the quality and availability of hospice and palliative care services across the country. The results were recently published in the form of state-by-state “report cards.” Although Colorado got a couple of good grades (specifically with respect to care in intensive care units (ICUs) at the end of life, and state advance directives policies), the report card for the state indicated a number of areas in need of improvement. (See Table 6 at the end of this chapter.) Most important, Colorado needs to:

- Increase the number of hospitals with pain management, hospice and palliative care programs;
- Decrease the percentage of nursing home residents in persistent pain;
- Increase the percentage of state residents who die at home;
- Increase the percentage of deaths with hospice stays and the median hospice length of stay;
- Decrease the percentage of nursing home residents in persistent pain;
- Improve the level of support for palliative care in the state’s pain policies; and
- Increase the percentage of primary care physicians, primary care sub-specialty physicians, and registered nurses who are certified in palliative care.

Commentary

There is a fair degree of consistency between the findings of this feasibility study and those of the two major recent studies briefly described above. With respect to an assessment of Colorado’s end-of-life system, they all point to the need for better training of health care professionals and improved education of patients, caregivers and the general public in order to improve the quality of life of those at the end of their lives.

Recommendations

- ⇐ The main focus of efforts to improve Colorado's end-of-life and palliative care system should be on community education, training health professionals, making it easier for patients to access and afford care, support for families and caregivers, and improved community collaboration.

- ⇐ The best way to meet systemwide needs may be by creating some kind of center or it may be by simply expanding current efforts, particularly in the areas of community education, training, research, and hospice and palliative care.

Table 6

**Colorado Report Card on the Availability and Use of Care for Dying Americans:
Results of a Study by the Last Acts Coalition**

Criteria	Measure	Grade
<ul style="list-style-type: none"> Care in ICUs at the End of Life: <i>How many elderly people spend a week or more in intensive care units during the last six months of life?</i> Percentage of state residents > age 65 with 7 or more ICU days totaled across all admissions during the last 6 months of life, 2000 	4.7	A
<ul style="list-style-type: none"> State Advance Directives Policies: <i>Do state policies support good advance care planning?</i> Quality of state advance directive laws, 2002 	3.5 on a scale of 0 to 5	B
<ul style="list-style-type: none"> Location of Death: <i>What proportion of the state's deaths occur at home?</i> Percentage of state residents who died a home, 1997 	29%	D
<ul style="list-style-type: none"> Hospice Use: <i>Is hospice care widely used in the state?</i> Percentage of deaths with hospice stays, 2000 	36.8%	C
<ul style="list-style-type: none"> Hospital End-of-Life Care Services: <i>Do the state's hospitals offer pain and palliative care services?</i> Percentage of hospitals self-reporting pain management programs, 2000 Percentage of hospitals self-reporting hospice programs, 2000 Percentage of hospitals self-reporting palliative care programs, 2000 	50% 20.3% 17.2%	C D E
<ul style="list-style-type: none"> Pain Among Nursing Home Residents: <i>How well do the state's nursing homes manage their residents' pain?</i> Percentage of nursing home residents in persistent pain, 1999 	47.2%	D
<ul style="list-style-type: none"> State Pain Policies: <i>Do state policies encourage good pain control?</i> State pain policies' level of support of palliative care, 2001 	5 on a scale from -3 to +9	C
<ul style="list-style-type: none"> Palliative Care-Certified Physicians and Nurses: <i>Does the state have enough physicians and nurses who are trained and certified in palliative care?</i> Percentage of primary care & primary care subspecialty physicians who are certified in palliative care, 2000 Percentage of estimated number of full time equivalent registered nurses who are certified in palliative care, 2000 	0.34% 0.35%	C C
<p>Source: "National Group Gives Colorado Mixed Ratings on End-of-Life Care," Last Acts, press release, November 18, 2002.</p>		

II. The Need for a Colorado Center for End-of-Life and Palliative Care

Major Findings

- ✓ Most of the Colorado people interviewed for this study either said a Colorado center is definitely needed or is needed but only if it is structured properly.
- ✓ Those who qualified their support said the center has to be practical, serve the entire state and not just Denver, be a genuinely collaborative endeavor, and not threaten funding for existing programs.
- ✓ The three most important ways supporters said they thought a center could make a difference were: 1) people will die better and quality of care will be improved; 2) Colorado will have a central information resource; and 3) more people will have access to good palliative and end-of-life care.
- ✓ The most important need centers in other parts of the country say they are meeting is to serve as a source of practical information and assistance.

Introduction

The central question the feasibility study addressed was whether or not there is a need for a Colorado center for end-of-life and palliative care. The previous chapter looked at the larger issue of systemwide needs in Colorado's end-of-life system. This chapter looks more narrowly at the specific question of the need for a Colorado center. To answer this question, Yondorf & Associates interviewed knowledgeable Coloradans and examined the operations in centers in other states to see what needs they were meeting. This chapter reports the results of those inquiries.

Colorado Interviewee Preferences

Colorado hospice directors, community group representatives and other knowledgeable people were asked the following question: "There has been some discussion about creating a Center for End-of-Life and Palliative Care in Colorado that would work with communities and professionals to improve end-of-life care. How would you assess the need for such a center?" Their responses are shown in Table 7.

Most interviewees favored the creation of a Colorado center for end-of-life and palliative care. However, nearly two-thirds of supporters qualified their support based on how they thought the center should be set up and what its focus should be. Hospice directors were the most likely to express conditional, as opposed to unconditional, support for the creation of a center. Six

Table 7				
Colorado Interviewee Support for Creation of a Colorado Center for End-of-Life and Palliative Care				
Survey Question: "How would you assess the need for a Colorado center that would work with communities and health professionals to improve end-of-life care?"				
Respondent	Definitely Needed	Needed But Only if Structured Properly ^b	Other Projects Have Higher Priority ^b	Not Needed
Consumer representatives	4	4	0	0
Hospice executive directors ^a	2	10	4	0
Other knowledgeable people	5	5	2	1
TOTAL	11	19	6	1
^a One person said she did not have enough information to answer the question. ^b See text for more detail.				

respondents thought other projects were of higher priority. Just one person did not see a need for a Colorado center. Interviewee responses are discussed in more detail below.

Proponents

Of the 38 Colorado individuals and groups interviewed for the study, 11 (29%) said, without qualification, that a Colorado center for end-of-life and palliative care is definitely needed. They offered three main reasons. First, a concentrated, coordinated effort is required to achieve fundamental changes in the health care system. Second, Colorado needs a single entity to serve as a central education, resource and referral center for health care providers, patients, caregivers and the general public. Third, as the number of people requiring end-of-life and palliative care grows, the need to have an organization that provides statewide leadership on issues related to end-of-life and palliative care becomes paramount.

Need a coordinated effort to change the system. Several interviewees talked about the need for a fundamental shift in public and provider attitudes about/acceptance of death and dying. They also said that the health care system needed to become more responsive to the needs not just of those with acute conditions but also of those with chronic disabling and terminal illnesses. The following are sample comments from those expressing this concern:

- *We need to create a continuous system where there aren't abrupt changes from one type of care to another. Patients need an informed, gradual sense of transition, not a sudden shift. Death with dignity and care driven by what the patient wants are key.* [Member of the Metro Black Church Initiative]
- *In order to thrive and progress, we need our own center. The challenge is how to inspire practitioners to change the way they do business.* [Experienced nonprofit organization director]

- *Somebody has to take leadership and responsibility for changing the status quo.* [UCHSC faculty member]

Need a central resource center. Those who support the establishment of a Colorado center for end-of-life and palliative care because they see the need for a central resource center made comments such as the following:

- *If a center is not established, families and even professionals will continue to flounder trying to identify resources and find information.* [Consumer group representative]
- *There is a need for coordination and education, a place where ethical issues can be discussed and policies and standards can be set.* [Denver nurse specialist]

Need leadership to address growing problem. Some people favored creation of a Colorado center because the aging of the population and other demographic trends demand that Colorado pay more attention to end-of-life and palliative care issues. One person said:

- *There's lots of need but a dearth of resources. Boomers are on the cusp. Demand will really escalate in a short time. Of girls born this year, 50% are expected to live into their nineties.* [Palliative and hospice care expert]

Conditional supporters

Nineteen interviewees (50%) said they would favor the creation of a Colorado center for end-of-life and palliative care, but only under certain circumstances. There were four main concerns conditional supporters expressed. First, the center needs to be practical. Second, it needs to be a collaborative model. Third, the center must address statewide needs and pay particular attention to the needs of rural providers. Fourth, funding for a new center should not draw resources away from existing activities. Examples of the comments of those expressing conditional support for a center are listed below.

Condition: a practical center.

- *The center needs to be practical. This is really important stuff, especially as health care costs continue to escalate. But the problem with a center is that nothing really practical comes from a center.* [Health care network representative]
- *A center is needed but only if it's really useful, does concrete activities, helps people doing patient care. Don't do it if it adds a lot of tap dancing but no real meat.* [Rural physician]

Condition: collaborative model.

- *The center must include leadership from around the state contributing to the model and not all the funding should go to the University.* [Director of a nonprofit consumer organization]
- *End-of-life care needs to be collaborative. A true interdisciplinary model is critical [to having the center] working right. Hospices must be partners. It's their business. They have huge numbers of employees to be trained.* [Hospice director]

- *Must be a collaborative process, not an Ivory Tower. [What's needed is] a respectful infrastructure and people with a shared vision and passion. [UCHSC faculty member]*

Condition: statewide resource.

- *The center needs to focus on areas of the state that don't already have good hospice, palliative care resources. [Social worker]*
- *Geographic barriers [to end-of-life care] are a big deal outside of Denver, something that Denver is not sensitive to. [Palliative care expert]*
- *The center should provide services and funding in rural Colorado, especially for inpatient respite care. [Rural hospice provider]*
- *Don't make people come to Denver for services. Need development of resources locally. [Palliative care nurse]*

Condition: not threaten funding for existing programs

- *A center should be established only if essential funding for day-to-day care of patients by hospice and palliative care programs is not sacrificed. [Western Slope provider]*

Interviewees who have other priorities

Six people said that while there may be a need for a center, investing in other activities or projects should be a higher priority. These people included four hospice directors and two health care providers who are not involved in end-of-life or palliative care on a day-to-day basis. They recommended funding the following projects in lieu of establishing a Colorado center for end-of-life and palliative care:

- Standardization of care and nurturing what we have;
- Funding for palliative care given before hospice care;
- Direct funding of hospice providers and the Colorado Hospice Organization;
- Development of new and novel therapies; and
- Alzheimer's disease research.

One person said:

- *I can't see a full-time need for such a center. But I can see it as part of a larger picture. [Physician]*

Opponent

One person (a social worker) did not see the need for a center. She felt that existing information resources were sufficient to meet her needs and those of the patients and families with which she works. Her biggest concern was lack of funding for hospice care for undocumented persons.

Important Difference a Center Could Make

Yondorf & Associates asked those interviewees who expressed either unqualified or conditional support for a center what important difference they thought a center could make. Their responses are shown in Table 8.

The three most important ways supporters of a center said they thought a center could made a difference were: 1) people will die better and quality of care will be improved; 2) medical professionals, patients, caregivers and the public will have a central information resource; and 3) more people will have access to good palliative and end-of-life care. Supporters also said that establishment of a center could lead to patients and families having a better understanding of their options, an increase in the number of trained palliative care and end-of-life professionals, and greater acceptance of dying as a normal process.

Table 8		
Important Difference that a Center Would Make— Colorado Interviewee Opinions		
Survey Question: “If you think a Center is either definitely needed or needed if structured properly, what important difference do you think a Center would make?”		
Rank	No. Who Cited this Difference ^a	Difference a Center Would Make ^b
1.	8	People will die better, quality of care will be improved.
2.	6	Medical professionals, patients, caregivers and the public will have a central information resource.
3.	5	Access to good palliative and end-of-life care will be available to more people.
4.	4	Patients and families will have a better understanding of their options.
	4	Colorado will have more trained professionals in palliative and end-of-life care.
	4	Dying will be more accepted as a normal process, less feared.
5.	3	The public and state leaders will be better informed.
	3	Cost savings will be realized from greater, more appropriate use of palliative and hospice care.
6.	2	Good end-of-life care will be established as a priority in its own right.
	2	There will be consistent standards of practice across all Colorado hospices.
	2	The center will open doors to more referrals and funding.
^a Some people cited more than one difference. ^b Only lists differences cited by two or more people.		

Examples of comments made by interviewees include:

- *A center will give professionals a kick in the butt to want to be trained on this, including the need to be comfortable with themselves and with death and dying.* [Consumer advocate]
- *If the goal is to make Denver a better place to live, let's make Denver a good place to die too. We want a strong economy and good schools, why not good end-of-life care?* [Director, community nonprofit organization]
- *A center will establish end-of-life care as a priority in its own right.* [Western Slope consumer]
- *A center would mean there was one place to go for direction or access to educational/informational materials on end-of-life care decision making and issues.* [Home and hospice care nurse]

One hospice director who was a qualified supporter of a center said, when asked what difference a center could make, "I'm not convinced it would make a huge difference."

The Experience in Other States

There are at least 13 other centers for hospice, palliative care, and/or end-of-life studies around the country. (See Appendix A.) As part of the feasibility study, Yondorf & Associates collected detailed information on the history and operations of seven of these centers—centers that represent different types and sizes of organizations. (See Table 3 on page 13.) Yondorf & Associates looked into the needs those centers are meeting. More specifically, feasibility study staff asked center executive directors and staff what prompted the creation of their centers. They also examined the centers' mission and vision statements.

Catalysts for the creation of other centers

The catalysts for the creation of centers in other states were diverse. For example, the origin of the Midwest Bioethics Center was a group of people interested in ethics and health care. They began by hiring someone to interview individuals and groups of people (nurses, doctors, lawyers, professors, ethicists, etc.) regarding their interest in a potential center. At the University of Florida, what was to become the Center for Hospice, Palliative Care and End-of-Life Studies grew out of meetings held by people in the College of Nursing who wanted to stimulate interest in potential research projects. They found a common interest in end-of-life issues.

Several of the centers, such as The Center for Excellence in End-of-Life Education, Research and Practice outside of Buffalo and the Maggie Allessee Center in Michigan, began when the hospice organizations of which they were a part decided that they needed a formal locus of activity related to training and research. The San Diego Hospice had been conceived of as a teaching and research center from the beginning, and in that sense the creation of its Center for Palliative Studies was an outgrowth of its original intent.

Center mission statements

Mission and vision statements are an important source of information about the role that end-of-life and palliative care centers play in other states. Table 9 on the next page shows the mission and vision statements for seven centers. An examination of these statements suggests that a

Table 9

Examples of Mission and Vision Statements from Centers in Other States

Program	Mission and/or Vision Statement
The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)	<u>Purpose:</u> To create an innovative and enduring national template for exemplary end-of-life education, research and practice, and improve the way in which end of life care is presented to our future practitioners and practiced by our community's health care providers.
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	<u>Mission:</u> To optimize care and systems of care for patients and families affected by advanced non-curable diseases by generating new knowledge through interdisciplinary research, using that knowledge to educate health and human service professionals, and influencing public policy that supports quality end of life care.
The Center for Palliative Care Studies at San Diego Hospice (CA)	<u>Purpose:</u> To coordinate and foster education, research and advocacy for hospice and palliative care.
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY	<u>Mission:</u> To increase the availability of palliative care services in hospitals and other healthcare settings for people with life-threatening illnesses, their families and caregivers.
The Hospice Institute of the Florida Suncoast	<p><u>Mission:</u> To provide communities, volunteers and professionals training, research, resources and education to improve end-of-life care; evaluate models to improve palliative and end-of-life care; and define and conduct clinical and organizational research to advance end-of-life practice and influence end-of-life public policy initiatives.</p> <p><u>Vision:</u> The Hospice Institute of the Florida Suncoast is the leading center for end-of-life education, research and innovation.</p>
Maggie Allesee Center for Quality of Life, Hospice of Michigan	<u>Vision:</u> To foster new ways of thinking about quality of life and death, and the wide variety of issues that people face at the end of life through collaborative approaches at the local, state and national levels; and to be a leader in demonstrating how to bring new knowledge and tools regarding end-of-life to people in a way that will empower them to live more fully and to advocate for themselves and their loved ones.
Midwest Bioethics Center (MO)	<p><u>Mission:</u> To raise and respond to ethical issues in health and healthcare.</p> <p><u>Vision:</u> A society in which the dignity and health of all people is advanced through ethical discourse and action.</p>

central need that all of the centers are addressing is to serve as a source of practical information and assistance for the wide range of people and institutions engaged in end-of-life and palliative care. Other important goals are to:

- Provide model educational programs for students, providers, and health institutions;
- Conduct research regarding, and identify and disseminate information about, best practices;
- Influence the medical profession;
- Coordinate research objectives related to end-of-life and palliative care;
- Help shape public policy; and
- Educate the public.

Recommendations

- ⇐ It appears that, at minimum, there is a need for some kind of statewide coordinating/clearinghouse function. Colorado needs a central, statewide source for practical information, assistance, and referrals that serves both health care professionals and the public, and that coordinates existing efforts in the state.
- ⇐ Whether or not a formal center is needed is not clear. There are several less expensive alternatives that might be able to meet the same needs that supporters of a center see it meeting. What is clear is that whatever is done should be the result of a collaborative process focused on maximizing the use of existing local and national resources.

III. Activities of a Colorado Center

Major Findings

- ✓ Colorado interviewees said the most important activities of a Colorado center should be to: improve and enhance training of health professionals; facilitate collaborative projects at the community level; conduct and disseminate research on financing, reimbursement and improved models of care; and assist the public and providers to link up with appropriate resources.
- ✓ The major activities that centers in other states engage in are to: train health care professionals; sponsor community education programs; produce educational materials; conduct research; develop curricula; engage in community collaboratives; provide technical support; and serve as a resource center.

Introduction

There are a number of things a Colorado center for end-of-life and palliative care might do. For example, it could sponsor educational programs, work to improve access to palliative care, or support existing palliative and hospice clinical care services. It could develop models of care delivery for individuals with serious and progressive diseases; serve as a resource center; or conduct research in palliative and hospice care delivery and reimbursement. Other possibilities might include advancing palliative care as a key component of all care, or working to improve the quality of end-of-life and palliative care. To find out what activities a Colorado center for end-of-life and palliative care could/should undertake, Yondorf & Associates researched the activities of seven centers in other states, and asked Colorado interviewees for their opinion.

The Experience of Other States

Yondorf & Associates looked in some detail at the operations of seven centers around the country that focus on end-of-life and palliative care. (See center charts in Appendix D.) As part of that process, staff gathered data on the centers' major activities. (See Table 10 on the next page.⁶) Our analysis shows that the major activities state centers engage in are training and educating health care professionals, sponsoring community education programs, and producing educational materials. They also conduct research; develop curricula for health care professionals; and collaborate with community partners on special projects. Some of the centers advocate for improved end-of-life care and palliative care, while others provide technical support to hospitals, hospices, and long-term care facilities.

Most centers place a major emphasis on training health care professionals. Almost all of the centers offer some form of community education program and/or produce literature and videos. Some of the programs have a strong focus on research, such as the University of Southern Florida and the Center for Palliative Studies in San Diego.

⁶ For more detailed center-by-center information, look under the heading "Major Activities" in Appendix D--Detailed Informational Charts for Seven Centers.

<p>Table 10</p> <p>Most Common Activities of Seven Centers that Focus on End-of-Life and Palliative Care Issues *</p>
<p>Most Common Activities</p>
<ul style="list-style-type: none"> • Train and educate health care professionals • Sponsor community education programs • Write articles, manuals, pamphlets and guidelines; produce videos, tool kits, etc. • Conduct research • Develop curricula, certificate programs for health care professionals • Collaborate with community partners on special projects • Advocate for improved end-of-life care, palliative care, and other related issues • Provide technical support to hospitals, hospices, long-term care facilities, etc. • Serve as a resource center
<p><i>* See Table 3 for a list of the seven centers.</i></p>

Yondorf & Associates also gathered information about specific projects undertaken by the centers. Table 11 lists a few examples.

<p>Table 11</p> <p>Selected Examples of Center Activities</p>	
Type of Activity	Examples
Train health care professionals	<ul style="list-style-type: none"> • Teach palliative care medicine to health care professionals at the undergraduate, graduate and postgraduate levels (Center for Excellence—Buffalo, NY)
Sponsor community education programs	<ul style="list-style-type: none"> • Offer programs on care giving issues, self-advocacy and advance directives (Center for Excellence--Buffalo, NY) • Sponsor seminars, speakers bureau, tours, booths at health fairs, etc. (Center for Palliative Studies—San Diego) • Train patients and families on living with chronic illness (The Hospice Institute of the Florida Suncoast)
Produce materials, videos, etc.	<ul style="list-style-type: none"> • “A Model to Guide Hospice Palliative Care” (Center for Palliative Studies—San Diego) • “Building Access to End-of-Life Care” (The Hospice Institute of the Florida Suncoast) • Video: “The Future of Dying” (Midwest Bioethics Center—Missouri)
Conduct research	<ul style="list-style-type: none"> • Project: “Hospice Care Utilization by Medical Oncologists in Cancer Centers” (Center for Excellence--Buffalo, NY) • Study of depression at the end-of-life (Center for Hospice, Palliative Care and End-of-Life Studies--Univ. of So. Fla)
<p><i>(continued on next page)</i></p>	

Table 11 (continued)	
Selected Examples of Center Activities	
Develop curricula, certificate programs	<ul style="list-style-type: none"> • Construct interdisciplinary curricula for all professionals who render palliative care to the community (The Center for Excellence—Buffalo, NY)
Collaborate on community projects	<ul style="list-style-type: none"> • Assist community groups in developing ethics centers in various states (Midwest Bioethics Center—Missouri) • Sponsor telehospice project (Maggie Allesee Center for Quality of Life—Michigan)
Do advocacy	<ul style="list-style-type: none"> • Advocate for the alignment of university research projects with the needs of hospice and other end-of-life practitioners (The Hospice Institute of the Florida Suncoast) • Advocate for the addition of palliative care to medical school curricula (Midwest Bioethics Center—Missouri)
Provide technical support to health care institutions	<ul style="list-style-type: none"> • Assist hospital-based palliative care programs (Center to Advance Palliative Care—New York) • Sponsor course in “Advanced Hospice Accounting” (The Hospice Institute of the Florida Suncoast)

Colorado Interviewee Preferences

Yondorf & Associates asked Colorado interviewees what they thought should be the highest priority activities for a Colorado center for end-of-life and palliative care. Their responses are shown in Table 12 on the next page.

Among all respondents, the most highly rated activities were: 1) improve and enhance training of health professionals; 2) facilitate collaborative projects at the community level to improve end-of-life care; and 3) conduct and disseminate research on financing, reimbursement and improved models of care. However, consumer group representatives, hospice directors, and other knowledgeable interviewees each rated a different activity as most important:

- For consumer group representatives, the highest priority was assisting the public and providers to link up with appropriate resources.
- For hospice directors, it was improve and enhance training of health professionals.
- For others it was facilitate collaborative projects at the community level to improve end-of-life care. Another activity that was rated high by this third group but not other interviewees was advocacy for end-of-life and palliative care.

Table 12

**Highest Priority Activities for a Colorado Center—
Colorado Interviewee Opinions**

Survey Question: “If a Center for End-of-Life and Palliative Care were to be established in Colorado, which of the following do you think should be the Center’s three highest priorities?”

Overall Rank	Priorities for a Center ^{a, b}	No. Who Cited as Priority		
		Consumer Representatives	Hospice Executive Directors	Other Knowledgeable People
1.	Improve and enhance training of health professionals.	4	14	6
2.	Facilitate collaborative projects at the community level to improve end-of-life care.	3	7	8
3.	Conduct and disseminate research on financing, reimbursement and improved models of care.	2	8	4
4.	Assist the public and providers to link up with appropriate resources.	5	2	4
	Disseminate best practices information to providers and the public.	1	4	6
5.	Advocate for end-of-life and palliative care issues.	1	5	3
6.	Work to improve access to palliative care.	3	4	1
	Promote ongoing dialogue about ethical, legal and moral issues related to end-of-life care.	3	2	3
7.	Provide clinical advice to palliative care providers.	1	2	2
	Foster better two-way communication between academia and community providers of care.	0	4	1

^a Multiple responses permitted.

^b Only lists priorities cited by two or more people.

Recommendation

- ⇐ If a Colorado center is established its initial priorities should be those identified by Colorado interviewees. They include: working for more and better training of health professionals; facilitating community collaborative projects, in part by building on the work of The Colorado Trust Palliative Care Initiative; encouraging research on financing, reimbursement and improved models of care; and assisting the public and providers to link up with appropriate resources.

IV. Existing Resources

Major Findings

- ✓ There are a number of organizations in Colorado engaged in training, education, public outreach, research, advocacy, collaborative community projects, consultations, or patient/family support with respect to end-of-life and palliative care. However, there is no central coordination of these efforts and, in many cases, people are not aware of who is doing what or where to go for help. Also, there is no locus of responsibility for filling in the missing pieces in the system or monitoring and improving Colorado's end-of-life system as a whole.
- ✓ Colorado interviewees think that the role of a Colorado center in relation to already existing programs should be to collaborate with them in such a way as to enhance their efforts.

Introduction

There are a number of programs in place, both in and outside of Colorado that, at least to a limited extent, provide some of the possible services of a Colorado end-of-life center. If a Colorado center on end-of-life and palliative care were to be created, it would need to be clear about what its role would be in relation to already established programs. This chapter looks at a few of the major programs that are already in place locally and nationally and explores what they do, who they serve, and how patients, providers, families and others concerned about end-of-life care in Colorado use them. What is presented is not intended to be an exhaustive list of programs but rather a representative sample to give the reader a sense of some of the types of programs that are already in place.

Examples of Local Programs

Several organizations in Colorado are engaged in research, training, community education, community collaboratives, advocacy, technical assistance, and/or public policy development with respect to end-of-life and palliative care. A few of the major ones are briefly described below.

University of Colorado Health Sciences Center (UCHSC)—health professionals training⁷

UCHSC sponsors several courses and programs on end-of-life care as part of its training of medical, nursing and pharmacy students. For example, first-year students in the medicine, physical therapy, physician assistant and pharmacy programs, and second-year students in the nursing school are required to take an ethics course, which includes a session on death and dying issues. Third-year medical students are required to take a clinical internal medicine rotation that includes decision-making on end-of-life care and a one-day hospice experience.

⁷ Sources: Phone conversations with Mark Yarborough, UCHSC (January 24, 2003), and Jean Kutner, MD, UCHSC (January 27, 2003).

Electives are available in end-of-life issues and include an experience where students partner with a terminally or chronically ill person for four to six weeks. Pediatric residents attend noon brown bag lunches throughout their three-year training program. Between three and six of those programs each year deal with such topics as grief and bereavement, and withholding and withdrawing artificial nutrition and hydration. A knowledgeable UCHSC faculty member said the medical school's curriculum does not deal explicitly with palliative care.

UCHSC--Population-based Palliative Care Research Network⁸

The Population-based Palliative Care Research Network (PoPCRN) is based in the Division of General Internal Medicine at UCHSC, and directed by Dr. Jean Kutner. PoPCRN conducts research in palliative care settings in an effort to enhance end-of-life care for patients, families, caregivers and providers. Its research network consists of a voluntary group of programs in Colorado and across the country that provide care in private homes, nursing facilities, and freestanding hospices. Clinicians, administrators, and researchers collaborate under PoPCRN to ensure that the program's research projects are both clinically relevant to practitioners in the field and well-designed to yield valid information. Examples of recent PoPCRN study topics include: psychosocial and spiritual issues among hospice patients; symptom burden at the end of life; and the role of hospices in educating nurses and doctors. In 2002, PoPCRN received a national Circle of Life Award in recognition of its "exciting collaboration between organizations that provide palliative care and a university health sciences center doing population-based research that promises to improve the way end-of-life care is provided nationwide."⁹

Note regarding Dr. Jean Kutner. In the course of conducting the feasibility study, it became apparent that PoPCRN and its director, Dr. Jean Kutner, are very highly regarded, both locally and nationally. Several people made a special point of saying how helpful and accessible Dr. Kutner is. This was true not only among researchers, academics and other center directors but also among hospice providers and other interviewees.

UCHSC--Center for Bioethics and Humanities¹⁰

The Center for Bioethics and Humanities at the University of Colorado Health Sciences Center "exists to inspire a balance between the sciences and humanities in health care delivery and research." Center faculty work with other health care organizations and the public to promote greater awareness of, and craft solutions to, ethical issues in health care. For example, the Center for Bioethics works collaboratively with clinicians at the Children's and University of Colorado Hospitals both to increase awareness about the importance of appropriate care at the end of life, and to improve health professionals' training in this area. Center faculty played a major role in starting the Palliative Care Service at University of Colorado Hospital. The Center also serves as an important state resource for information, technical assistance, and training on clinical and ethical issues in end-of-life and palliative care.

Colorado Hospice Organization (CHO)

CHO is a nonprofit corporation that was founded in 1980 and is dedicated to promoting the hospice concept of care and serving as a voice and resource for its hospice provider members. According to its materials, "CHO's advocacy for the hospice concept of care includes professional and lay education, legislative efforts, and the provision of technical assistance to

⁸ Sources: 1) PoPCRN web page: <http://www.uchsc.edu/popcrn/> and 2) "Circle of Life Award 2000," American Hospital Association,

⁹ The award is sponsored by the American Hospital Association, American Association of Homes and Services for the Aging, and the National Hospice and Palliative Care Organization; The Robert Wood Johnson Foundation funds the award.

¹⁰ Source: Funding Proposal for End-of-Life and Palliative Care submitted to Rose Community Foundation by the Center for Bioethics and Humanities, UCHSC, March 6, 2002.

developing hospices. Access to quality hospice care for all Coloradans is at the core of CHO's vision."¹¹ Each year CHO holds a Fall and Spring Conference, plus a Bereavement Skill Building Day. These conferences attract a broad array of people interested in hospice and palliative care. The 2002 Fall Conference included more than 30 sessions and three special workshops. CHO participates in a number of community organizations. It is a member of the Colorado Coalition for the Medically Indigent, Colorado Gerontological Society, Colorado Minority Health Forum, Colorado Rural Health Center, Pain Management Consortium, and PoPCRN Advisory Committee.¹² CHO is going through a transition period as its widely respected executive director, Al Canner, is leaving the organization. In the future, it plans to more narrowly focus its efforts on education, standards and public policy.

Hospice Alliance of Colorado¹³

Hospice Alliance of Colorado includes seven of the state's larger hospices that have come together "to increase access to quality, comprehensive hospice care across the state."¹⁴ These seven hospices represent some of the state's most established and experienced hospice providers, serving approximately two-thirds of Colorado's hospice patients. According to the organization's web page, the Alliance offers health care providers and third-party payers an easily accessed, comprehensive hospice network in Colorado. The members of the Alliance engage in joint contracting and have also worked together on educational and joint purchasing projects.

Local hospices

Most of Colorado's hospices are active in their communities, providing not only hospice and palliative care but also educational programs and materials for patients, families and the general public. Many also participate in research and demonstration programs and are central players in local community collaboratives on hospice and end-of-life care. Several sponsor special health professionals training programs and/or have students who visit, rotate through, or work at the hospice as part of their professional training. For example, in the area of health professionals training, Hospice and Palliative Care of Western Colorado recently established the Western Slope Palliative Care Institute. The Institute is designed to serve as "a hub for educational programs devoted to building the capacity of health care professionals to better serve the needs of patients and families facing the crises of terminal illness." Hospice of Metro Denver (HMD), which is already heavily involved in training medical, nursing, social worker, chaplain and other students, has plans to set up a formal End-of-Life Institute. The Institute will be "a collaborative regional institute that trains physicians and nurses in the intricacies of palliative care."¹⁵

The Colorado Trust Palliative Care Initiative¹⁶

The Initiative is a three-and-a-half year program, begun by The Colorado Trust in 2000. It is designed to improve palliative care in Colorado communities. Eight grantees around the state have been funded by the Initiative to coordinate care through palliative care networks in order to

¹¹ Source: "Hospice in Colorado," Colorado Hospice Organization, January 1, 2002.

¹² Source: Handouts from the CHO Annual Meeting, October 11, 2002.

¹³ Source: Hospice Alliance of Colorado website: <http://www.hospicecolorado.org/about.htm>

¹⁴ The hospices are: Hospice of Boulder County, Hospice and Palliative Care of Western Colorado, Hospice of Larimer County, Hospice of Metro Denver, Hospice and Palliative Care of Northern Colorado, Pikes Peak Hospice and Palliative Care, and Sangre de Cristo Hospice.

¹⁵ Source: "Comfort: The Capital and Endowment Campaign for Hospice of Metro Denver" brochure.

¹⁶ Sources: 1) "Grantmakers in Health Bulletin," May 15, 2000. Website: http://www.gih.org/usr_doc/53869.pdf; 2) "Palliative Care Initiative Overview," The Colorado Trust.

improve the quality of palliative care provided to individuals facing progressive, chronic, life-threatening or terminal conditions.

CARE Connection (serving Denver) has a special focus on people suffering from Alzheimer's and other late-stage dementias. Pueblo Palliative Care Initiative (serving Pueblo) offers services to medically fragile children, adults of all ages, persons with developmental disabilities, and those affected by Alzheimer's and AIDS. Supportive Care Network (serving Denver) is focusing on improving palliative care services for infants, children and adolescents, and establishing an Internet-based medical record system. The Larimer County Palliative Care Initiative (serving Larimer County) is implementing a community case manager pilot project. The L.I.F.E. Network (serving Mesa County) is offering palliative care services to patients and families through the L.I.F.E. model. L.I.F.E. refers to locating resources, interventions for symptom management, family and caregiver support, and education of patients, families, physicians and community.

Three grantees are working to improve access to and quality of palliative care in rural areas. They include: West End Uncompahgre Palliative Network (serving western Montrose County and the town of Norwood); Palliative Care Partners (serving Alamosa, Conejos, Costilla, Mineral, Rio Grande and Saguache counties); and Caring Connections...Living Beyond Wellness (serving Garfield, Pitkin and western Eagle Counties).

Kaiser Permanente¹⁷

Kaiser Permanente is doing a number of interesting things, both locally and nationally, with respect to end-of-life care. Among other things, it is working with its local hospice vendors, chronic special needs and aging case managers, primary care physicians, oncologists and others to increase the appropriate use of hospice and palliative care. The organization has an end-of-life advisory committee and a web site for its members, has established a Kaiser Permanente Aging Network Leadership Council, put together a Palliative Care Source Book, and has sponsored a teleconference on end-of-life care. In recent years, Kaiser Permanente has devoted significant resources to researching the best ways to provide end-of-life care so as to maximize the cost-effectiveness of, and patient satisfaction with, end-of-life care for its members. Currently it is looking at best practices and gaps in care in the areas of dementia and palliative care. It is also investigating the value of providing hospice services to certain populations who have a prognosis of more than 6 months. Kaiser Permanente has worked with UCHSC, and Dr. Jean Kutner in particular, on the education of its physicians in end-of-life care.

QuaLife Wellness Community¹⁸

QuaLife Wellness Community is a Denver nonprofit organization that offers programs "to assist in finding wellness while in the midst of illness." It uses a "wholistic approach that acknowledges the whole person and the body, mind, emotions and spirit being that we each are." QuaLife offers support groups facilitated by professionals, including groups for newly diagnosed, ongoing treatment, recurrent disease, chronic illness/chronic pain, past treatment/in remission, and grief. The organization sponsors a comprehensive support program for breast cancer patients and their families; weekend programs designed to empower patients, families and friends to attain a greater sense of healing and well being; classes and work shops; individual services; healing gardening; and expressive arts. QuaLife is a teaching facility, hosting interns from area colleges and universities in such fields as art, music and horticultural therapy, psychotherapy, the ministry, and marketing. It is a leader in the psycho-oncology field

¹⁷ Source: Interview with Dr. Glenn Gade, Operations Chief, Medical Subspecialties, Kaiser Permanente, September 30, 2002.

¹⁸ QuaLife Wellness Community web page: <http://www.qualife.org>

and has provided expertise to local, national and international organizations. QuaLife's board of directors is diverse and community-based.

Possible new Denver metro coalition to improve end-of-life care. Recently, QuaLife has taken the lead in hosting a series of meetings with people from a broad spectrum of organizations in the Denver metro area who are involved in or concerned about end-of-life issues. The purpose of the meetings has been to gauge interest in the possible creation of some kind of metro Denver alliance to improve end-of-life care. The alliance would be formed as a Rallying Points Program. (See description of Rallying Points on the next page.) Notes from a meeting of interested parties held in November 2002 indicate that the mission of the group would be "to inspire and create community-based education, dialogue and action in support of those at the end of life, and their families and friends."¹⁹ Possible activities for the new alliance might include physician peer-to-peer education, community conversations to stimulate conversation about death and dying, advocacy around policy and regulations, improving relations between doctors and patients, eliminating barriers to accessing end-of-life services, and expanding on ethnically multicultural training/agencies.

Colorado Healthcare Ethics Forum (CHEF)²⁰

The Colorado Healthcare Ethics Forum is an organization designed to provide a forum for chairs and members of Colorado hospital-based ethics committees to discuss ethical issues. CHEF has three goals: 1) to establish contacts with others interested in hospital-based ethics throughout Colorado; 2) to create a forum to share information and policies; and 3) to share ethics related educational opportunities with each other. The organization maintains a Web page and sponsors annual meetings. CHEF is directed by a board that includes UCHSC faculty interested in health ethics and current and former chairs of hospital ethics committees. It is an Allied Professional Organization affiliated with the Colorado Hospital Association.

Examples of National Resources

A number of national organizations provide information and advice, conduct research, and sponsor educational programs that are used by Colorado patients, providers, community groups academic programs and others interested in end-of-life and palliative care issues. Some of the better known programs are briefly described below.

Last Acts²¹

Last Acts is a national coalition of organizations engaged in an education campaign to improve care for people who are near death or dying and their families. Partner organizations represent consumer groups, health care professionals, religious bodies, advocates, educators and health care institutions. Last Acts serves as a clearinghouse for sharing information and ideas at the national, state and local levels. Its working groups and committees study issues and create products to address family needs, institutional change, professional education, palliative care, financing, and the workplace. The organization sponsors national and regional conferences, publishes a quarterly print newsletter and special reports, has an e-mail newsletter, and publishes new information on its web site. Last Acts also helps partners find experts, identify

¹⁹ Source: "Notes from Break-out Groups, End-of-Life Coalition 'Test Drive' Gathering on November 15, 2002," QuaLife Wellness Community.

²⁰ Source: Colorado Healthcare Ethics Forum website: <http://www.uchsc.edu.chet>

²¹ Source: Last Acts website: <http://www.lastacts.org>

speakers and publicize Partner Activities products and efforts. Last Acts is headquartered at Partnership for Caring, Inc., in Washington DC. It is funded by The Robert Wood Johnson Foundation.

Rallying Points²²

Rallying Points is a major initiative of Last Acts. (See Last Acts description above.) It provides technical assistance grants to community-based coalitions to improve care and caring for those nearing the end of life. It encourages coalitions to identify community needs for better end-of-life care, advocate for health system changes to bring about better care, and develop specific projects that support dying people and their families.

The National Hospice and Palliative Care Organization (NHPCO)²³

The National Hospice and Palliative Care Organization is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization works to improve end-of-life care and expanded access to hospice care across America. It advocates for the terminally ill and their families. It also develops public and professional educational programs and materials to enhance understanding and availability of hospice and palliative care; convenes meetings and symposia on emerging issues; provides technical informational resources to its membership; conducts research; monitors Congressional and regulatory activities; and works closely with other organizations that share an interest in end-of-life care.

The Center to Advance Palliative Care (CAPC)

The Center to Advance Palliative Care at Mount Sinai Medical School in New York City is a resource for hospitals and health systems interested in developing palliative care programs. The Center serves a broad constituency of providers and interested groups, including physicians, nurses, educators, policymakers, health researchers, payers, students and, ultimately, patients and their families. It is committed to improving the availability and quality of palliative care. CAPC is a national initiative supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Mount Sinai School of Medicine. (For more detailed information on CAPC see the center chart for the program in Appendix D.)

Education for Physicians on End-of-life Care (EPEC)

Education for Physicians on End-of-life Care is a program designed to educate all physicians on the essential clinical competencies required to provide quality end-of-life care. The core of EPEC's offerings is a curriculum consisting of four 30-minute plenary modules and twelve 45-minute workshop modules. It teaches fundamental skills in communication, ethical decision-making, palliative care, psychosocial considerations, and pain and symptom management. The Project is supported by the Robert Wood Johnson Foundation and sponsored by The Feinberg School of Medicine at Northwestern University in Chicago.

End-of-Life Nursing Education Consortium (ELNEC) Project²⁴

The End-of-Life Nursing Education Consortium project is a comprehensive, national education program to improve end-of-life care by nurses. The 13 total courses sponsored by the ELNEC

²² Source: Rallying Points website: <http://www.rallyingoints.org>

²³ Source: National Hospice and Palliative Care Organization website: <http://www.nhpc.org>

²⁴ Source: www.aacn.nche.edu

project are designed to meet the needs of several specific groups of nursing educators. These include baccalaureate and associate degree nursing faculty who will facilitate integration of end-of-life care in basic nursing curricula (five courses), and state board of nursing representatives to strengthen their commitment to encouraging end-of-life care education and practice initiatives in their states (one course). They also include nursing continuing education providers and clinical staff development educators who will offer educational activities to improve the end-of-life care by practicing nurses. This group includes nurses providing continuing education in colleges and universities, state and specialty nursing organizations, and independent businesses, as well as continuing education/staff development in clinical settings such as hospitals, hospices, home care, and long term care (seven courses). The project is funded by a major grant from The Robert Wood Johnson Foundation.

Midwest Center for Bioethics²⁵

The Midwest Center for Bioethics houses the Community-State Partnerships Program, a national Robert Wood Johnson Foundation program that funds and supports broad-based, multidisciplinary coalitions working to promote policy change and support for high-quality, comprehensive end-of-life care. The grants support statewide coalitions working with citizens, health care professionals, educators and policymakers to identify problems, make recommendations and build public support for practical policies, regulations and guidelines to improve care of the dying. (For more detailed information on the Midwest Center for Bioethics see the center chart for the program in Appendix D.)

Promoting Excellence in End-of-Life Care²⁶

Promoting Excellence in End-of-Life Care is a regional resource center for Rallying Points (see previous page), located in Montana. It provides technical assistance, networking opportunities and workshops to address issues of common concern to those working in local communities to improve end-of-life care. It serves western states including Colorado.

The Hospice Institute of the Florida Suncoast

The Hospice Institute of the Florida Suncoast is an international center that offers education and training sessions, conducts research, and provides consultation services related to end-of-life issues. It offers education and training materials and other resources for hospice staff, volunteers and communities. (For more detailed information on The Hospice Institute of the Florida Suncoast see the center chart for the program in Appendix D.)

Growth House, Inc.²⁷

Growth House, Inc., which is based in San Francisco, provides online information and referral services for agencies and individuals working on death and dying issues. The Growth House search engine offers access to a substantial collection of reviewed resources for end-of-life care. It promotes public education and professional collaboration, has national and international links, hosts chat rooms and a network with access to more than 70 e-mail lists. Growth House, Inc., is also a full-service technical consulting firm specializing in end-of-life care.

²⁵ Source: Midwest Bioethics Center website: <http://www.midbio.org>

²⁶ Source: Promoting Excellence in End-of-Life Care website: <http://www.promotingexcellence.org/>

²⁷ Source: Growth House website: www.growthhouse.org/

Usual Sources of Information

Colorado interviewees were asked to identify the resources that they turn to most frequently for assistance on end-of-life and palliative care issues. They were also asked about the kinds of information they sought from these programs. Their answers are shown in Table 13.

Consumer group representatives, hospice directors, and other knowledgeable interviewees all cited the **Colorado Hospice Organization (CHO)**, and **Last Acts** as major information sources.

Hospice directors rely on CHO and NHPCO for information about regulations, rules, compliance, technical assistance, consultations, program development, hospice statistics and trends, legislation and advocacy, educational opportunities and professional training. Some

Table 13		
Usual Sources of Information about End-of-Life and Palliative Care Identified by Colorado Interviewees^a		
Survey Question: "What national, state and local resources do you turn to for assistance on end-of-life or palliative care questions?"		
Respondent	Usual Sources of Information	Types of Information Sought
Consumer representatives		
	<ul style="list-style-type: none"> • Local hospices • Colorado Hospice Organization • Last Acts • Churches, faith-based organizations • Disease-specific organizations 	<ul style="list-style-type: none"> • Availability of hospice care and related services • Options for patients and families • Referrals • Miscellaneous information
Hospice executive directors		
	<ul style="list-style-type: none"> • National Hospice and Palliative Care Organization • Colorado Hospice Organization • Center to Advance Palliative Care (NY) • Last Acts • Other hospices 	<ul style="list-style-type: none"> • Regulations, rules, compliance • Technical assistance, consultation, program development • Hospice statistics and trends • Legislation and advocacy • Educational opportunities, professional training
Other knowledgeable people		
	<ul style="list-style-type: none"> • Colorado Hospice Organization • Last Acts • University experts • National Hospice and Palliative Care Organization • Center to Advance Palliative Care (NY) 	<ul style="list-style-type: none"> • Literature for professionals, patients, families • Availability of hospice care and related services • Technical assistance, advice • Best practices
^a This table only lists the top five most frequently mentioned sources of information and most frequently cited types of information sought.		

also turn to the **Center to Advance Palliative Care (CAPC)** at the Mount Sinai School of Medicine in New York or the **Last Acts** coalition for similar information.

Several consumer group representatives mentioned **churches, faith-based organizations, and disease-specific organizations** (e.g., Alzheimer's Association, Huntington's Disease Society, etc.) as other important sources, in addition to CHO and Last Acts. They turn to these organizations for information about the availability of hospice care and related services, options for patients and families, and referrals.

In addition to CHO, Last Acts, NHPCO and CAPC, other knowledgeable interviewees (primarily those in academia) said they turned to **university experts** for information on end-of-life and palliative care issues. The types of information that they sought most frequently were literature for professionals, patients and families; information on the availability of hospice care and related services; technical assistance and advice; and best practices data.

These findings suggest that CHO comes the closest of any organization in Colorado to being a central information source for consumers, experts in the field, hospice directors, and other knowledgeable people. However, CHO does not advertise itself as a center on end-of-life and palliative care and clearly has as its primary purpose to meet the needs of its member hospices.

Colorado Interviewee Opinions

As was already mentioned in Chapter II, "The Need for a Colorado Center," Colorado interviewees believe that if a Colorado center is created, it needs to collaborate with other existing organizations. They think it should enhance rather than duplicate what existing programs are already doing. As one consumer organization director put it, "Resources need to be value-added, where people can take action." A person with experience in starting up new organizations said, "If it's a collaborative process, everything can be done. Each partner can identify what they do best." This person went on to say that the role of a Colorado center should be to foster a collaborative model where efforts would not be duplicated.

Yondorf & Associates Observation

In the course of researching local and national end-of-life programs and talking with Colorado interviewees, it became apparent that many of those involved in and/or concerned about end-of-life care were not aware of all the resources at their disposal. There were several occasions where feasibility study staff actually played a role in linking up different groups. For example, the director of one program focusing on families with dying children who wanted to do active community outreach was unaware of a local consumer group with similar concerns and a large group of community outreach workers. In another instance, an organization engaged in end-of-life research was unaware of PoPCRN. Often people were not aware of the national resources that are available. These findings underscored the need identified by a number of interviewees for a central information clearinghouse.

Recommendation

- ← 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.

V. The Audience for a Colorado Center

Major Findings

- ✓ Colorado interviewees said the primary audiences for a Colorado center should be: physicians, nurses and social workers; academic medical/health programs; the general public; and hospitals and hospices.
- ✓ The four primary audiences for centers in other states are: practicing community health care professionals; academic medical/health programs; those interested in end-of-life research; and health care institutions.

Introduction

There are many different possible audiences for a Colorado center for end-of-life and palliative care. They include hospice providers, pain clinics, hospitals, caregivers, social workers, families, patients, academic researchers, and health foundations. Other audiences include government health agencies, accrediting agencies and regulatory bodies, health professionals training programs, health delivery system managers, and managed care organizations and insurers. Public officials, state and local health planners, the general public, the media, and public and private purchasers of health care are also likely to have an interest in the work of the center. Moreover, some of the center's work could be directed at one audience while other aspects of its work might be directed at other audiences. Yet trying to serve too many masters is likely to dilute the center's effectiveness. This chapter looks at who could/should be the primary "customers" for a Colorado center.

The Experience in Other States

In its examination of centers for end-of-life and palliative care in other parts of the country, Yondorf & Associates found that most centers have four primary audiences. They are practicing health care professionals in the community, academic medical/health programs, those interested in end-of-life research, and health care institutions (e.g., hospices, hospitals, etc.). (See Table 14 on the next page.²⁸)

Center executive directors were asked not only about their primary audiences but also about the types of people from whom they most often receive phone calls. Many said they receive calls from hospitals and medical personnel interested in either research or getting hospice and palliative care advice. The director of the Institute of the Florida Suncoast said that she receives phone calls from people with all sorts of different backgrounds and situations asking, "How do we do this?" The director of the Midwest Bioethics Center said she hears from legislators, researchers, clinicians and families. A professor at the University of South Florida center reported recently receiving calls from physicians submitting grants concerning palliative

²⁸ For more detailed center-by-center information, look under the heading "Primary Audience(s)" in Appendix D--Detailed Informational Charts for Seven Centers.

Table 14	
Primary Audiences for Seven Centers in Other States *	
Rank	Primary Audience
1.	Practicing health care professionals in the community
	Academic medical/health programs
	Those interested in end-of-life research
	Health care institutions (e.g., hospices, hospitals, etc.)
2.	General public, families and patients
3.	Medical students and other health care professionals in training
4.	Other: policymakers, government agencies, health care systems, social services systems, trade and professional organizations, and foundations
* See Table 3 for a list of the seven Centers.	

care in the intensive care unit. Some center staff get calls asking them to participate in national panels and committees. All have been contacted to provide educational resources for the community.

Colorado Interviewee Preferences

As part of its survey of knowledgeable Coloradans, Yondorf & Associates asked who the primary audience(s) for the work of a Colorado center for end-of-life and palliative care should be, if one is created. Interviewees were given a list of possible types of people/groups and asked to select no more than three. Their answers are shown in Table 15 on the next page.

There was general agreement among all those interviewed that physicians, nurses and social workers should be the most important audience for a center. “Start with those on the front lines,” was the recommendation of one expert. Another said, “The priority should be people out there providing care. It’s not fair to be precepting or training students or responding to an activated public if they’re not prepared for it.” But there was not the same unanimity among consumer group representatives, hospice directors, and other knowledgeable interviewees when it came to identifying other priority audiences.

Consumer group representatives felt nearly as strongly that patients and families, as well as physicians, nurses and social workers, should be a primary audience. For hospice directors, their number two audience of choice was academic programs. For others, it was hospices, hospitals, nursing homes and home health providers.

One person who is active in the policy arena felt strongly that Colorado public policymakers need to be a priority audience. He commented, “If they don’t support what you’re doing, how do you get the change you need?” Another person thought that it was important to focus on the media as the best way to reach patients and families. A third who is an experienced program director recommended a three-phase approach:

Start with the physicians and the academic community. You have to have the power structure on your side—they’re the key to changing the medical infrastructure. Then work with the hospices. Finally, with the first two partners in place, reach out to consumer advocacy groups and the general public. [Denver palliative care expert]

Table 15

**Primary Audiences for a Colorado Center—
Colorado Interviewee Opinions**

Survey Question: “Which of the following do you think should be the three primary audiences for a Colorado Center if one is created?”

Overall Rank	Primary Audience ^{a, b}	No. Who Selected Audience		
		Consumer Representatives	Hospice Executive Directors	Other Knowledgeable People
1.	Physicians, nurses, and social workers	7	14	9
2.	Academic programs	2	11	2
3.	General public	3	8	3
4.	Hospices and hospitals	1	8	4
5.	Patients and families	5	2	3
6.	Nursing homes and home health providers	0	3	4
	Colorado public policymakers	1	4	2
7.	Consumer health and health advocacy groups	1	2	3
8.	Media	2	2	1

^a Multiple responses permitted.
^b Only lists audiences cited by two or more people.

Recommendation

- ⇐ The major audiences for a Colorado center or coordinating/clearinghouse entity should be practicing community health professionals, academic medical/health programs, the general public, and health care institutions.

VI. Level of Funding Needed to Establish a Center

Major Findings

- ✓ Estimates of the amount of money necessary to start a center range from \$100,000 to \$600,000 for the first year. Several centers in other parts of the country started as very small programs and have grown considerably over time.
- ✓ The centers that were examined for this study have annual budgets ranging from \$200,000 (for one of the brand new centers) to \$3.2 million.
- ✓ Research grants and foundation support are the major outside sources of funding for end-of-life and palliative care centers.
- ✓ Center directors in other states and several Colorado interviewees said sustainability of a Colorado center is a major issue and that a plan of solvency for the center should be developed at the outset.

Introduction

The level of funding necessary to establish and sustain a center for end-of-life and palliative care depends on a number of factors, including the organization's mission, desired staff and staffing levels, the number and types of projects the center intends to take on, and availability of funding. This chapter examines the budgets of and sources of funding for centers in other parts of the country, and the funding necessary to start a center.

Other Centers' Budgets and Financing Sources

Yondorf & Associates collected information on the budgets and major funding sources of seven centers working on end-of-life and palliative care issues. Table 16 on the next page summarizes the results.²⁹ It should be noted that while the executive directors and senior staff of other centers were quite forthcoming on most topics, few were willing to share detailed information about their budgets, funding sources, or start-up costs. Feasibility study staff concluded that the hesitance about sharing this kind of information had to do with the fact that many of the centers see themselves as competing for foundation funding and staff.

Budgets

Of the seven centers across the country that Yondorf & Associates contacted, only five were willing to share information about their budgets. Among those five centers, budgets range from \$200,000 (estimated) to \$3.2 million per year. (See Table 16.) In most centers, at least half of

²⁹ For more detailed center-by-center information, look under the headings "Annual Budget and Breakdown" and "Main Funding Sources" in Appendix D--Detailed Informational Charts for Seven Centers.

Table 16

Budgets and Main Funding Sources for Seven Centers in Other States

Center	Annual Budget	Main Funding Sources
The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)	[Center did not supply its budget]	<ul style="list-style-type: none"> • Local foundation • Grants • In-kind support from parent organization^a
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	[Center did not supply its budget. However, an analysis of funding sources suggests it is currently about \$200,000.]	<ul style="list-style-type: none"> • Local hospices • Cancer and research institute • University of South Florida Health Sciences Center
The Center for Palliative Care Studies at San Diego Hospice	\$1 million	<ul style="list-style-type: none"> • Grants • Small endowment • Parent organization^b
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY	[Center did not supply its budget]	<ul style="list-style-type: none"> • Major national foundation
The Hospice Institute of the Florida Suncoast	\$1.25 million	<ul style="list-style-type: none"> • 50% - Fees for services provided to parent hospice • 50% - Grants Parent foundation^c Limited revenues from sales of products and services
Maggie Allessee Center for Quality of Life, Hospice of Michigan	\$3.2 million	<ul style="list-style-type: none"> • 68% - Parent organization^d • 12% - Grants • 6% - Bequests • 6% - Third party payer revenue • 5% - Direct mail • 3% - Special Events
Midwest Bioethics Center (MO)	\$1.6 million	<ul style="list-style-type: none"> • Donor gifts • Grants • Membership contributions • Revenue from consultations, videos, etc.
<p>^a The parent organization is The Center for Hospice and Palliative Care. ^b San Diego Hospice. ^c Hospice Foundation of the Florida Suncoast. ^d Hospice of Michigan.</p>		

the budget is used for staff salaries and benefits. The center with the lowest budget—the Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida—is brand new.

Funding Sources

Major funding sources for centers in other states include the parent hospice of the center in those instances where the center is a program of the hospice, research grants, and foundation support. Two centers reported collecting limited revenues from the sale of products or services. Several said they received donor gifts and bequests. The Center for Palliative Care Studies at San Diego Hospice has a small endowment and the Midwest Bioethics Center has members who make contributions.

Start-Up Costs

Yondorf & Associates asked the executive directors of several centers how much seed money they thought a Colorado center would need to get off the ground. Directors were, for the most part, hesitant to recommend a figure. Many of the centers started with one staff member at a hospice or university expressing an interest in end-of-life issues. Over time that person brought in more staff and funds to support his/her efforts until the organization essentially blossomed into a full-fledged center. One center began with \$300,000 and another with approximately \$100,000 per year for three years.

A center director who has advised a number of programs around the country recommended a start-up budget of \$3 million for five years. An experienced Colorado nonprofit director who has “birthed” many similar programs suggested a start-up annual budget of \$500,000.

Colorado Organizations’ Willingness to Provide Funding, Staff

Coloradans interviewed by Yondorf & Associates were asked whether the organizations for which they work might be willing to provide funding and/or staff resources to help ensure the sustainability of a Colorado center, if one were created. In asking the question, feasibility study staff noted that monetary contributions could be in the form of dues, fees charged for certain services, a nominal annual fee to have access to the services of the center, or in some other form. Table 17 on the next page shows the responses.

Of the 32 individuals and groups who answered the question about financial/in-kind support, approximately one-third said yes, they thought their organization would be willing to contribute some funds and possibly some staff time to the center. Another third either said their organization might, under certain circumstances, contribute funds or could only offer limited staff support. The final third said no, their organization probably would not be able to contribute either funding or staff resources to the endeavor.

Those who said their organizations might be willing to contribute some funding to help sustain a center under certain circumstances qualified their support in several different ways. A number of respondents made it clear that they could only afford very modest contributions—either inexpensive fee-for-service charges for specific services or a modest annual fee. One person thought her organization might be willing to pay membership dues but only if they perceived that the center offered something different than was already available from other organizations.

Table 17

Likelihood that Survey Respondents’ Organizations Would Provide Funding and/or Staff Support for a Colorado Center

Survey Question: “Do you think the organization for which you work would be willing to provide funding and/or staff resources to help ensure the sustainability of a Center if one were created?”

Respondent	Organization Likely to Provide Financial Support?			
	Yes	Qualified Yes ^a	Limited Staff Support Only	No
Consumer representatives	1	0	2	4
Hospice executive directors	6	5	0	4
Other knowledgeable people	3	2	2	4
TOTAL	10	7	4	11

^a See text for more detail.

Most of those who said their organizations would be unlikely to provide funding or staff support cited their own straitened fiscal circumstances. The director of a consumer advocacy organization said, “just funding our own organization is a challenge.” A hospice director explained, “We are in [a rural county] and a nonprofit in need of our own funding.”

Overall, hospices were the most likely and consumer organizations the least likely to say they probably could/would provide some, albeit limited, financial and/or in-kind support for a Colorado center for end-of-life and palliative care.

A Note About Sustainability

Most of the centers for end-of-life and palliative care in other parts of the country with whom Yondorf & Associates spoke reported concerns about sustainability. Several are trying to set up endowments. At least one center noted that while it still has a healthy operating budget, it is approximately 25% less than it had been at one time. A number of the directors talked about the importance of tuning their programs to the needs of the community, specifically so that they could attract funding. Those centers that appeared to have the most secure funding bases are either part of a large existing hospice that purchases services (e.g., education, training, etc.) from the center or have received large, multi-year grants or bequests to fund their work.

Several Colorado interviewees also expressed concerns about the sustainability of a Colorado center. Some noted the history of prior attempts in Colorado to establish and institutionalize some kind of ongoing, partnership program concerned with end-of-life issues. They worried that, like those efforts, a Colorado center might not be able to be sustained over the long term. (For more information on past efforts in Colorado, see Chapter VIII, “Additional

Lessons From Other States and Observations by Colorado Interviewees.”) An experienced program administrator who oversees a number of grant-funded projects recommended that “a plan of solvency be developed at the outset.” He said, “It is important to have a vision and worry about sustainability.”

Recommendation:

- ← Given the large sums required to start up and sustain a center and the reality of limited resources, it is recommended that a phased approach be adopted. The first two steps should be to:
 - Convene interested parties to identify ways in which, with modest additional funding, they could expand on their current activities to address system needs, and identify those needs that cannot be met through existing programs.
 - Consider funding a coordinating/ clearinghouse position. This may go a long way toward solving some of the most important unmet needs in the system. Also, it may be that by housing such a position in an organization that already has the capacity to carry out many of the roles of a center, a *de facto* center will be the result. This latter outcome is especially likely if linkages among existing programs can be formalized.

VII. Establishing a Colorado Center: Organizational Issues

Major Findings

- ✓ There is no consensus about where to locate a Colorado center. Some think it should be at the University of Colorado Health Sciences Center (UCHSC) in the Center for Bioethics and Humanities. Others (mainly hospice directors) think it should be administered out of the Colorado Hospice Organization (CHO). Still others want it housed in a freestanding nonprofit or in some other location.
- ✓ A number of people who selected a location other than UCHSC either strongly opposed locating a Colorado center there or expressed serious reservations.
- ✓ For many people, the preferred model is some sort of co-equal partnership between the community and the University.
- ✓ Experienced center directors and Colorado interviewees said that the executive director of a center should have a track record of success in building programs and a passionate interest in the subject, and should be a great collaborator.

Introduction

Yondorf & Associates researched three critical questions with respect to how a Colorado center for end-of-life and palliative care might be organized. First, if a center is established, where should it be housed? Second, how should the center be staffed? Third, what types of people should sit on the board? Each of these questions is explored in some detail in this chapter.

Organizational Setting

Centers in other states are located most commonly in a university or as part of an existing hospice. However some, such as the Midwest Bioethics Center, are independent, freestanding organizations. Table 18 on the next page shows how seven centers in other states are organized.

As part of its survey of knowledgeable Coloradans, Yondorf & Associates asked where a Colorado center should be located and why. The top three choices among interviewees were 1) in the Center for Bioethics and Humanities at the University of Colorado Health Sciences Center (UCHSC), 2) as part of the Colorado Hospice Organization, and 3) in a freestanding nonprofit created just for this purpose. (See Table 19 on the next page.)

Table 18	
Examples of Different Center Organizational Models	
Type of Activity	Examples
Hospice-based	<ul style="list-style-type: none"> • The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY) • The Center for Palliative Care Studies at San Diego Hospice • The Hospice Institute of the Florida Suncoast • Maggie Allesee Center for Quality of Life, Hospice of Michigan
University-based	<ul style="list-style-type: none"> • Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida • Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY
Independent, freestanding	<ul style="list-style-type: none"> • Midwest Center for Bioethics (MO)

Table 19				
Preferred Organizational Location for a Center— Colorado Interviewee Opinions				
Survey Question: “If a Colorado Center for End-of-Life and Palliative Care is established, in which of the following organizational settings should it be located?”				
Overall Rank	Where to Locate a Center	No. Who Selected Location		
		Consumer Representatives	Hospice Executive Directors	Other Knowledgeable People
1.	At the Center for Bioethics & Humanities, University of Colorado Health Sciences Center	4	3	5
2.	As part of the Colorado Hospice Organization	0	10	1
3.	In a freestanding nonprofit created just for this purpose	2	3	3
4.	In some other academic setting	0	0	2
5.	As part of an existing hospice or health network	0	1	0
6.	In some other place: <ul style="list-style-type: none"> • In the community, outside of the University 	2	0	0
7.	<ul style="list-style-type: none"> • In an agency outside of the University but associated with it • In a model similar to the American Cancer Society 	0 0	0 0	1 1

The sections below describe the four organizational models that either most Colorado interviewees said they favored or are common homes for centers in other states. They include a university-based center, a center housed at the Colorado Hospice Organization, an independent freestanding center, and a hospice-based center.

University-based

A university-based center is one that is located in a university as part of an existing department or program. Among the seven centers in other states investigated for the feasibility study, two use this model. They are the Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida, and the Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY. There are, however, a number of other centers that were not included in this study that are also located in universities. (See list and locations of centers in Appendix A.)

The major advantages of locating a center for end-of-life and palliative care at a university include the credibility and stature that a university lends to the endeavor, the ability to access the broad resources of the university, and the ability to attract top-flight staff. The major disadvantages include the frequent inability of some university researchers to produce timely responses to practitioner or policymaker requests and needs, high university overhead costs, and university politics and bureaucracy.

Twelve (32%) of the 38 Colorado individuals and groups who were interviewed for the feasibility study favored locating a Colorado center at the UCHSC's Center for Bioethics and Humanities. This was the highest-ranked option among all those considered by interviewees. (See Table 19.) It was the first choice of consumer group representatives and non-hospice leaders and experts. Examples of comments in support of housing a center at UCHSC included:

- *The University of Colorado Health Sciences Center has a great name, it is building a premier facility, and they're training doctors. There would be a higher level of buy-in. It is the best [option] for credibility with the legislature. You can do a helluva lot more from within.* [Western Slope consumer]
- *What's good about the Bioethics Center is that it's not in any particular school. [The director of the Bioethics Center] has been a real advocate already. Putting [the center] in the University gives it legitimacy. It avoids turf battles of who is caring for whose patients.* [Academic physician]
- *There is obvious, appropriate expertise and interest expressed by UCHSC and the Center [for Bioethics]. Also, there may well be a better potential for continuing support at UCHSC than with other choices.* [Denver hospice director]

Two additional interviewees favored the university-based model, but preferred that the program not be housed at the Center for Bioethics and Humanities. One suggested the Department of General Medicine as a better home, explaining, "Bioethics is important but it's not involved in actual medical care delivery." A second recommended setting up the center as a freestanding program at UCHSC but apart from any existing centers because, "It's not just about bioethics."

Opposition to university-based. While a third of interviewees favored establishing a center at the UCHSC's Center for Bioethics and Humanities, several other interviewees were either strongly opposed to locating a Colorado center there or expressed serious reservations:

- *Universities create themselves as an island with their own culture and community. They create a wall.* [Director, nonprofit consumer organization]
- *If overseen by the University, [the center] will get lost, the University will control the money. It doesn't make a difference if it has an all-community board. It still will be stacked with people the University wants.* [Community nurse]
- *The University has very little historic commitment to palliative care, and often in higher education priorities are shifting constantly. It is an extremely bureaucratic environment for growing a new program. It also maintains a very Denver-focused approach to things. Programs at the University come and go on the whim of a dean or faculty coming and going.* [Hospice director]
- *Academia does not foster practice change. It fosters talk.* [Hospice director]

Concerns of minority interviewees. Several African-American and Hispanic interviewees expressed particular reservations about locating a Colorado center at UCHSC. In at least one instance, this was the result of bad experiences with University Hospital. The comment was, "When people come in [to University Hospital], they're put off by their initial meeting. They're made to feel like an imbecile." Another person said, "If I'm in Denver and have an eighth grade education, the University is not about me."

Trust and respect were two particular concerns voiced by minority interviewees when talking about a University-based center. One person associated with the Metro Denver Black Church Initiative said, "You need to create environments to give people the respect they're due." A person who works extensively with Hispanic patients said:

Trust of the medical profession is not very good. The Latino community feels it is not given all the options due to economic reasons. They don't feel like [we're] worth saving.

Despite these concerns, most minority interviewees were willing to consider housing a center for end-of-life and palliative care at UCHSC if it would work in partnership with the community.

Preference for a University-community partnership. Whether or not interviewees thought a Colorado center should be housed at UCHSC, most thought the University needed to at least be associated with the center in some way. A number of people suggested either a partnership arrangement or a division of responsibilities between the University and some other community-based organization.

One person suggested that the center be University-based but have a collaborative structure. Another recommended a "three-legged stool" involving UCHSC, the Colorado Hospice Organization, and a large hospice with a clear commitment to training and community education. A third said that a University affiliation is a good thing but perhaps the center also needed a partner in a rural area. Another thought that UCHSC should take the academic but not the fiscal lead for the project:

The center shouldn't be with the University in any fiscal way. [The University] has layers of bureaucracy that conflict. The Health Sciences Center doesn't have a good reputation in the community. [It's okay to] connect the center academically but not fiscally. The key is autonomy of funding source. Need accountability. [Palliative care expert]

Finally, three people recommended setting up the center as an independent, freestanding nonprofit that would be affiliated with the University. "You need co-ownership of practicing providers with the University," said one person.

Based at the Colorado Hospice Organization

Colorado hospice directors overwhelmingly favored locating a Colorado center at the Colorado Hospice Organization (CHO). CHO is a nonprofit corporation that is dedicated to promoting the hospice concept of care and serving as a voice and resource for its hospice provider members.

The major advantages of having a center for end-of-life and palliative care administered by CHO are that it has an excellent track record in advocating for and working to improve hospice and palliative care in Colorado, its members are the recognized experts on the delivery of end-of-life care, and it has a statewide presence with members all across Colorado. The major disadvantages are that it does not represent all those involved in end-of-life care, its top priority is responding to the needs of its hospice provider members, and it currently has just one staff person.

The main reasons hospice directors gave for wanting a Colorado center housed at CHO were: CHO members know the most about end-of-life care; CHO has a track record for getting things done; and the organization already has a statewide presence. One director said, "CHO has a vested interest in end-of-life care issues and serves on-the-line providers of care." A nurse who supports a CHO-based center said:

They're a step out there. They're close to public policymakers. They sit in the middle of the continuum, including providers in rural areas. They have experience, information, wisdom. They're tied nationally and the trend among hospices is to do palliative care.

Not everyone was supportive of having a Colorado center housed at CHO. In fact no consumer group representatives and just one non-hospice interviewee selected CHO as their first choice. Examples of reasons given for not backing CHO included, "The issues are broader than just hospice," and "[Placing the center in CHO] puts it in a particular niche; some families will never pick a hospice."

Yondorf & Associates did not identify any centers in other parts of the country that are located in a state hospice organization or other provider association.

Independent, freestanding

An independent, freestanding center is one that is not based in or specifically affiliated with any particular public or private organization, such as a university or hospice. The Midwest Bioethics Center in Kansas City, Missouri, is an example of a freestanding center.

The major advantages of establishing a center as an independent, freestanding nonprofit include neutrality and independence, the ability to be responsive and timely, and lack of bureaucracy. Disadvantages include that it may be harder to attract top-flight staff than under a university-based model, issues of sustainability, and high startup costs.

The independent, freestanding model was only slightly less popular among interviewees than the CHO option (10 versus 11 votes). But the support for an independent, freestanding center was more broadly spread among the different types of groups interviewed than the CHO option. (See Table 19.) Supporters said that an independent, freestanding organization created just for the purpose of being a center for end-of-life and palliative care would be, as one person put it, "the best to bring together the community, UCHSC, hospices, hospitals and health service networks." Several people liked this model because it would mean the center was not in a place where it was in competition with other institutions or providers in the community. Also, it

would be viewed as accessible and not politically connected to any group, and “it would stand on its own merit.”

Two people expressed concerns about establishing a new entity to house the center. The program director of a health services network counseled, “Don’t create another nonprofit that will compete for resources.” A community health worker said, “[The Center] shouldn’t be by itself. Death and dying shouldn’t be over there, alone.”

Hospice-based

A center that is hospice-based is one that is actually part of an existing hospice. Four of the seven centers in other states examined by Yondorf & Associates are programs that are part of a hospice organization. The Center for Excellence in End-of-Life Education, Research and Practice outside of Buffalo, NY, is part of The Center for Hospice and Palliative Care. The Hospice Institute of the Florida Suncoast is a program of The Hospice of the Florida Suncoast. Hospice of Michigan is the parent organization for the Maggie Allesee Center for Quality of Life. And the fourth center includes its location in its title—The Center for Palliative Care Studies at San Diego Hospice.

As was noted earlier in this report, the reason some centers are based in hospices is that it was the hospices themselves that first identified the need to get specialized training for their staffs and offer educational programs for patients, caregivers and the public. (See “Catalysts for the Creation of Other Centers” in Chapter II) Noting the absence of any other organization meeting this need, they decided to establish their own centers. For similar reasons, several Colorado hospices have organized their own “mini” end-of-life and palliative care centers to benefit their staffs and the local community. (See “Examples of Local Programs” in Chapter IV.)

The major advantages of establishing a center as part of an existing hospice are that hospices have a vested interest in having well-trained providers and an informed public, encouraging research that helps them deliver care more efficiently and effectively, and advocating for quality end-of-life care. The most significant disadvantages are that it means selecting one among many excellent hospices to run the program and a single hospice does not represent the wide array of organizations with an interest in end-of-life issues.

Among Colorado individuals who were interviewed for the feasibility study, only one recommended establishing a Colorado center in an existing hospice. This person, a hospice director, recommended that the center be run by a major hospice with a strong education, training and community outreach commitment. She also recommended that the medical school be affiliated with the center:

[Large hospices] have the infrastructure, expertise, clinical resources, and long-term commitment to house and grow such an endeavor. [A hospice-based center] could be structured collaboratively with the University and should be.

A rural nurse actively opposed the idea of locating the center in a hospice, saying, “Some have their own philosophy, their own bias.”

Advice from other states

Yondorf & Associates asked the directors of several end-of-life and palliative care centers in other states for advice about where to locate a Colorado center. The directors who were interviewed were divided in their opinions. Some favored a university setting because of a university’s ability to provide resources. Others were wary of a university-based center lest the

agenda of the center become subordinate to that of the university. At least one director thought it was essential that the center be freestanding.

Many spoke directly to the issue of maintaining good working relationships between academics and researchers, on the one hand, and non-academic community members and service providers, on the other. The Center for Hospice, Palliative Care and End-of-Life Studies at the University of South Florida addresses this issue regularly and directly. It has co-directors--one from the hospice community and one from the University. It has also carefully written its bylaws to maintain that balance on its oversight committees. Ron Schonwetter, Academic Director of the University of South Florida Center, noted that they work explicitly to maintain the involvement of the local hospices in the Center's developing work. Schonwetter said, "Collaboration is essential.... Those involved in research need to arrive at a common understanding of the needs of the community and match up their research." The Center's other co-director, Kathy Egan, who is also director of the hospice-based Hospice Institute of the Florida Suncoast, advised:

Do not base [the center] only in a university unless it is in partnership with end-of-life care providers. The funding could support governance such that the hospices always have someone involved.

Staffing

How a center for end-of-life and palliative care is staffed affects the kinds of projects it is likely to take on and how others perceive it. The following sections look at the kinds of skills the executive director and line staff of a center need.

Executive director

Yondorf & Associates researched the academic backgrounds and organizational experience of the executive directors of seven centers in other states. Table 20 on the next page shows the results.³⁰ Three executive directors have MD's and have been employed primarily in academic settings. Of the four executive directors who do not have MD's, three have MA's and one has a BA. Three of these directors have substantial experience as program managers and administrators in institutions such as hospices, social service centers and hospitals. Two have backgrounds in nursing. All but one of the executive directors have extensive backgrounds in hospice and palliative care, most often as health care providers but also as researchers or educators.

Yondorf & Associates asked key center staff in other states about the experience and qualities (beyond academic) they would look for in an executive director. Almost all said they would look for someone who has a track record of success in building programs. "An administrative type, a visionary," said one director. "Someone able to get along with a wide range of people, who can build coalitions," said another.

Several Colorado interviewees weighed in on the question of the type of person who should head a Colorado center. A Denver-based consumer advocate said the executive should have "a passionate interest and be a great collaborator." One hospice director thought it was important for the director to have hospice and palliative care experience.

³⁰ For more detailed center-by-center information, look under the heading "Director's Background" in Appendix D--Detailed Informational Charts for Seven Centers.

Table 20

Education and Experience of Seven Center Directors in Other States

Center and Director	Education	Experience
The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)		
Judith A. Skretny	MA. Academic training in religion and chemistry	Hospice program manager.
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida		
Ronald Schonwetter, Academic Director*	MD, Internal Medicine; certified in Hospice & Palliative Care Medicine; specialty in Geriatric Medicine	Academic. Also served as medical director for hospices and nursing facilities.
The Center for Palliative Care Studies at San Diego Hospice		
Charles F. von Gunten	MD, Internal Medicine; Ph.D., Biochemistry	Academic. Directed programs in hospice and palliative care, education and research at Northwestern Medical School.
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY		
Diane Meier, MD	MD, Internal Medicine; specialty in Geriatrics	Academic. Also is director of the Lillian and Benjamin Hertzberg Palliative Care Institute.
The Hospice Institute of the Florida Suncoast		
Kathy Egan	BA, Nursing; MA, Adult Education and Health	Nursing, education, counseling, social services and health care administration. Hospice background.
Maggie Allessee Center for Quality of Life, Hospice of Michigan		
Dottie Deremo	MA, Nursing; MA, Health Services Administration	Hospital program management, hospital executive administration.
Midwest Bioethics Center (MO)		
Myra J. Christopher	BA, Philosophy	Community involvement in schools, churches, etc.
<p>* Ronald Schonwetter is the Academic Director of the Center at University of South Florida. Kathy Egan is the Center's Community Director. Her education and experience are shown under The Hospice Institute of the Florida Suncoast.</p>		

Line staff

As part of its research, Yondorf & Associates collected information on the sizes and types of staff at seven centers in other states. (See Table 21.³¹) The Maggie Allessee Center for Quality of Life in Michigan has the largest staff, with 40.5 FTE. The brand new Center for Hospice, Palliative Care and End-of-Life-Studies at University of South Florida has the smallest staff, with 0.35 dedicated staff, although they anticipate increasing the staff by at least 1.0 FTE in the coming year. Another new center, The Center for Excellence in End-of-Life Education, Research and Practice in Buffalo, NY, has 2.5 staff. The other four centers have between 9 and 28 staff.

As the informational charts in Appendix D show, the types of staff each center has vary considerably. However, it is not uncommon to find a medical director as well as an executive director at a center for end-of-life and palliative care. Several centers also have directors of research, education and training, and community education and outreach. Three centers have staff positions to oversee volunteers who assist with such tasks as communications, record keeping, and data compilation. Other positions that may be found at some of the centers include an information technology and Web management person, fundraising and development director, events and/or communications person, and administrative personnel.

Center	Staff Size
The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)	2.5
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	0.35 ^a
The Center for Palliative Care Studies at San Diego Hospice (CA)	28
Center to Advance Palliative Care (CAPC) Mt. Sinai School of Medicine, NY	9
The Hospice Institute of the Florida Suncoast	14
Maggie Allessee Center for Quality of Life, Hospice of Michigan	40.5
Midwest Bioethics Center (MO)	13 ^b
^a Also considering adding 1.0 additional FTE. All other researchers associated with the University of So. Florida Center are not employees of the Center but instead are funded through their own departments. ^b This is the number of professional staff. In addition, there are administrative staff.	

³¹ For more detailed center-by-center information, look under the heading "Staff Size and Titles" in Appendix D—Detailed Informational Charts for Seven Centers.

Board composition

In its examination of seven end-of-life and palliative care centers in other states, Yondorf & Associates found that four have boards of directors. (See Table 22.³²) The size of the boards runs from 6 to 21. The Center at the University of South Florida constitutes its board half from University faculty and half from community members such as hospice representatives. The Midwest Bioethics Center in Missouri, which has 21 board members, has detailed guidelines for obtaining diversity and particular skills on its board. Two of the centers that do not have boards do have external advisory groups to provide comment and expertise on research and programs.

Table 22		
Boards of Directors for Seven Centers		
Center	Board Size	Types of People on the Board
The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)	6	Physicians, academic nurses, professor, clergy person.
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	12	Half university faculty, half community members (e.g., hospice representatives).
The Center for Palliative Care Studies at San Diego Hospice	---	[Does not have a board.]
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY	---	[Does not have a board; does have a National Advisory Committee.]
The Hospice Institute of the Florida Suncoast	16	This is a consultative board consisting of academics & community members (e.g., hospital representatives, volunteers, attorneys, etc.).
Maggie Allessee Center for Quality of Life, Hospice of Michigan	---	[Does not have its own board separate from the Hospice of Michigan board. However, it plans to set up an External Advisory Group.]
Midwest Bioethics Center (MO)	21	People with backgrounds in finance, clinical practice, philosophy and the law, and people from the community.

³² For more detailed center-by-center information, look under the heading “Board—Size, Membership, Who Appoints” in Appendix D--Detailed Informational Charts for Seven Centers.

In interviews with knowledgeable Coloradans, Yondorf & Associates asked about the types of people who should be on the board of a Colorado center, if one is established. Table 23 on the next page shows their responses. The types of people most frequently mentioned were hospice providers, physicians, academics and researchers, community leaders and the general public, nurses, public policymakers, and patients, families and caregivers.

A number of interviewees said it was important for the board to be multi-disciplinary and diverse—"a good mix." An experienced nonprofit director said:

The board should have physicians with an interest in the area; people with good research backgrounds; people who can make a difference (including those who can be champions and are decisionmakers in their organizations); and patients and families.

Several interviewees said "money people" should be on the board. Having "very influential people on the board in order to effect change" was deemed a high priority by one interviewee. A community health worker recommended having someone from the gay community, because gays and lesbians often face special legal problems at the end-of-life (e.g. who has visiting privileges, who can make medical decisions for the patient, etc.). Another person emphasized that the board not be too big. Finally, the director of a consumer advocacy organization urged involving people who are using or have used end-of-life care services: "People with experience can speak so well for the organization."

Recommendations

- ⇐ If a center or coordinating/clearinghouse position is established, it should be established where it can make maximum use of existing organizational resources. Ideally this would be in an organization that is already widely used, and generally considered to be an accessible, responsive and reliable source of end-of-life information.
- ⇐ Location of a center or coordinating/clearinghouse function should be decided through a consensus process that involves the major interested parties.
- ⇐ The people involved in a center or coordinating/clearinghouse function should have strong end-of-life and palliative care experience, and good facilitation and collaboration skills.
- ⇐ If a formal center is established, it should be modeled on the partnership arrangement between the University of South Florida and The Hospice of the Florida Suncoast.

Table 23

**Composition of the Board of Directors of a Colorado Center—
Colorado Interviewee Opinions**

Survey Question: “What types of people do you think should serve on the board of a Colorado Center for End-of-Life and Palliative Care if one is created?”

Rank	No. Who Recommended^a	Recommended Board Members^b
1.	20	Hospice providers
	20	Physicians
2.	14	Academics, researchers
3.	12	Community leaders and general public
4.	11	Nurses
5.	11	Public policymakers
6.	10	Patients, families, and caregivers
7.	7	Ethicists
8.	6	Lawyers
	6	Business leaders, money people
9.	5.	Clergy, faith-based community, pastoral counselors
	5	Social workers
	5	Nursing homes and other long-term care providers
	5	Hospitals
10.	3	Minorities

^a Multiple responses permitted.

^b Only lists board members cited by three or more people..

VIII. Additional Lessons From Other States and Observations by Colorado Interviewees

Major Findings

- ✓ Directors of centers in other states noted the importance of building partnerships, doing a needs assessment and market research prior to setting up a center, and being clear about the center's mission and focus.
- ✓ Several Colorado interviewees said they thought the overarching objective of the center should be to transform the medical system. They also talked about the role of an informed, energized public in spurring physicians to become better educated about end-of-life and palliative care; the need to pay attention to the palliative care needs of people with progressive, disabling conditions; and the importance of cultural competency in end-of-life care.
- ✓ Based on their experience with past Colorado efforts, Colorado interviewees recommended that if a Colorado center is created, it should be collaborative, inclusive and diverse; have a stable home and funding base; and be action-oriented.

Introduction

The previous chapters covered a number of lessons learned from other states and observations by Colorado interviewees about specific topics related to the establishment and operation of an end-of-life and palliative care center. In the course of the interviews conducted for this study, center directors and knowledgeable Coloradans voiced additional concerns and offered some additional advice. Colorado interviewees also touched on past efforts in Colorado to foster collaborative efforts aimed at improving access to and the quality of end-of-life care in the state. This chapter presents some of the main points that center directors and Colorado interviewees raised that have not already been discussed in previous chapters, and briefly describes past Colorado collaborative efforts on end-of-life issues.

Additional Lessons from Other States

- **Building partnerships is important.**

Many of the center directors from other states who were interviewed for the feasibility study underscored the importance of building partnerships to the success of a Colorado end-of-life and palliative care center. "You must build coalitions at the community level," said one director. "Extend hospitality to everyone who walks in the door" said another. A third said that if there is to be a successful center in Colorado it must begin with a meeting of the players from the diverse organizations and interest groups so that turf issues can be addressed at the outset.

- **The first step in setting up a center should be a thorough needs assessment and sound market research.**

Center directors in other states advised that the proposed center be founded with a careful assessment of the needs and strengths of the community and interest groups. This was thought to be a key to success in many respects, from fundraising to the ability to attract excellent staff. Don Schumacker, President and CEO of the National Hospice and Palliative Care Organization and former executive director of the parent organization that houses the Buffalo center, said that the center and its programs should arise “out of the community needs.” Frank Ferris of the Center for Palliative Studies at San Diego Hospice said, “Do an environmental scan asking where is the support coming from, what is the goal, who is interested, who are the players, what do we have, and what do we want to do?” Myra Christopher of the Midwest Bioethics Center said:

Do a community needs assessment, or market research. Identify who are the players. Pay attention to how to engage the key players. See if there is financial support in the community.”

- **Clarity of mission and focus are critical to the success of a center.**

The directors and key staff of centers in other states emphasized the importance of clearly articulating the mission and focus of a center. “Be clear about what you are doing” was the near universal advice of experienced center directors.

Additional Observations by Colorado Interviewees

- **Transforming the medical system is what the center should be about.**

A number of people raised this point. One said we need to shift from an environment where the medical practitioner tells the patient what he/she can do for the patient to one where the focus is on finding out what it is the patient wants. “The goal should be helping the patient to live as long as he can, as best as he can, as he defines it.” A Denver hospice director said, “We need to shift the dominant paradigm regarding the way the public views serious illness, the process of decline, and death itself.” A nurse counseled, “Don’t fund another medical model. It’s not the best way to deliver care.” A physician decried the fact that many of his colleagues are still holding onto a curative rather than a palliative care approach with patients who aren’t going to get better. Finally, an experienced nonprofit administrator said the vision for a Colorado center “should be to transform the way care at [the end-of-life] is thought about by people in training and practitioners.”

- **Cultural competency should be a key concern for the center.**

Several minority group interviewees said that cultural competency is important both in the training of health care professionals and for the staff of a center. One person who participated in the Metro Denver Black Church Initiative group interview noted that many African-Americans believe that if you put your mother or father in a nursing home, you’re throwing them away. Another participant noted the lingering impact of the infamous Tuskegee experiment on the willingness of Blacks to trust the health care system.³³

³³ The Tuskegee study refers to an infamous study of syphilis conducted between 1932 and 1972. During that period, 400 Black men were misled by officials of the U.S. Public Health Service about their medical condition and treatment. The men were told that they were being treated for “bad blood.” In fact, the men had syphilis and were deliberately left untreated in order to observe the progress of the disease.

In another interview, a Hispanic health care worker talked about differences in attitudes towards death and dying between the Hispanic and non-Hispanic White cultures. She said Hispanics tend to be more accepting of death and dying as a part of the natural order of things. Hispanics have the Day of the Dead (El Dia del Muerto), and make reference to death in their everyday lives. She noted that a common expression is *nacer para morir* (to be born to die). At the same time, it was emphasized that “Hispanic” is a term that encompasses many different people, yet “there is a tendency among health professionals and others to put all Spanish-speaking people together, regardless of country of origin or how long a person has lived here.”

- **The public should be able to easily access the center and its resources.**

This was the advice of an experienced administrator of a long-term care facility. A social worker echoed the same sentiment when she said, “[The center] shouldn’t be too academic because the common man won’t know to reach out or know the resource exists.” The associate director of a large community organization counseled that people shouldn’t have to “stumble on the existence” of the center or the information and resources that it has.

- **The center should not just focus on end-of-life care; it should also pay attention to the palliative care needs of those with progressively disabling conditions.**

An experienced nurse noted that there are people with serious palliative care needs who aren’t at the end of their lives. Examples include people who have “diseases of decline,” such as Huntington’s, Alzheimer’s or Parkinson’s Disease.

- **The best way to educate physicians may not be in the classroom.**

One experienced educator suggested that the best approach to getting physicians to be more capable with respect to end-of-life and palliative care may be to educate consumers so they come to their doctors with higher expectations. Physicians, he suggested, will more readily respond to a surge in patient demand than to efforts by outsiders to convince them that they should get more training. This was seconded by a rural physician who has trained a number of medical professionals and is “tired of ramming my head against the wall.” According to this person, “the answer is community—tell them here’s what you should ask [your doctor] for, here’s what you need to know.” Several people said it was important for students to actually spend time having a hands-on experience in a hospice setting. Another person suggested that the best way to change medical practice is to weave end-of-life and palliative care into the entire curriculum rather than treating it as a separate topic.

- **Remember that real change occurs from the bottom up.**

Just as getting physicians to take an interest in better end-of-life care may best be achieved by having an informed, demanding public, so too the best course of action to achieve other kinds of changes in the system may be to energize the public. This was a point emphasized by a health care provider with extensive academic and clinical experience. As an example, she argued that insurance companies will change their approach to coverage of and reimbursement for end-of-life and palliative care only when families demand it.

- **Consider using words other than “end-of-life” and “palliative care” in the center’s name.**

Three Colorado interviewees brought up this point. For many people, “end-of-life” and “palliative care” are either loaded or confusing terms. One provider who works with the

families of dying children said that her palliative care team talks about “supportive care.” A pastor suggested that a name such as “The Center for Life Transitions” would be more welcoming to his parishioners. A physician associated with a successful Denver-based program noted that hospice workers who came into his facility got a better reception from patients when they took off their hospice name tags and focused on “comfort care.”

Colorado Interviewee Lessons From Past Efforts

In the course of being interviewed for this feasibility study, several Colorado people talked about lessons that could be learned from past efforts in Colorado to set up a collaborative program focused on improving end-of-life care. The two past efforts that came up most frequently were the Colorado Collective for Medical Decisions (CCMD) and the Colorado Collaboration for End of Life Care (CCELC). Each of these two efforts is briefly described below, followed by a summary of lessons Colorado interviewees offered based on those two experiences.

The Colorado Collective for Medical Decisions³⁴

The Colorado Collective for Medical Decisions was an initiative begun by the Colorado Trust in 1995 to help answer sensitive questions about care for those nearing the end of life. The Collective brought together health professionals, policymakers, members of the clergy, community leaders, and members of the public to develop guidelines for appropriate end-of-life medical care—for the terminally ill, the permanently vegetative, and newborns with lethal birth conditions. Examples of other CCMD projects included public outreach campaigns, the development of a conflict resolution model, and the distribution of a series of brochures for patients, families and caregivers to help them talk with their health care providers about serious medical problems. The organization focused on promoting discussion between doctors and families about ethical and humane end-of-life care and public education. CCMD was set up as an independent nonprofit. The organization folded in 2000, in part because it had completed the initial agenda it had set out for itself and in part because its funding came to an end.

Colorado Collaboration on End-of-Life Care (CCELC)³⁵

The Colorado Collaboration on End-of-Life Care was a community project that included a variety of different organizations such as hospice programs and state health care professional associations involved in providing end-of-life care services. CCELC held its first meeting in August 1996. Particular areas of interest for the Collaboration were: pain management, communicating with patients, cultural issues and spiritual dimensions of suffering, and the economics and structure of end-of-life care. Among other things, CCELC distributed a newsletter, “Many Voices, Many Choices,” held several conferences and educational sessions, sponsored pilot studies, and, in cooperation with the Colorado Physician’s Insurance Company (COPIC), organized a series of seminars for physicians about pain management. One person attributed the demise of the Collaboration to unresolved disputes involving UCHSC, the executive director and community members about where to house CCELC and who should have primary control over the organization and its agenda.

³⁴ Sources: 1) Interview with Susan Fox (Buchanan), former executive director, Colorado Collective for Medical Decisions, December 3, 2002, 2) “Lessons in Death and Dying: Findings From the Grantmakers in Health Resource Center,” Grantmakers in Health, updated February 2000, web site: http://www.gih.org/usr_doc/49515.pdf, 3) “New Foundations in Health: Six Stories—The Colorado Trust,” Milbank Memorial Fund, May 1999, web site: <http://www.milbank.org/nf/colorado.html>

³⁵ Sources: 1) “Conference to Stimulate Discussion on End-of-Life Care,” *Robert Wood Johnson Foundation Grants Report*, December 1998. Website: www.rwjf.org/reports/grr/030689s.htm; 2) “End-of-Life Commissions and Education,” National Conference of State Legislatures. Website: www.ncsl.org/programs/pubs/conclusion.pdf; 3) Interview with Judy Hutchison, former CCELC executive director, November 19, 2002.

Lessons from Past Efforts

Colorado interviewees suggested that there were various lessons to be learned from the successes and failures of the CCMD and CCELC efforts. The major lessons they noted were that, if a center is created, it should:

- Be a truly collaborative, inclusive and open process with all the players at the table;
- Recognize and support existing efforts around the state;
- Understand that expertise resides in many places and settings around Colorado and not just at UCHSC, among academics, or in Denver;
- Have a stable home and a stable funding base;
- Be guided by a shared vision and mission supported by all interested parties;
- Not be dominated by physicians, academics, or a “handful of the elite,” and
- Be action-oriented.

Recommendation

- ⇐ Because it is clear that those involved in and concerned about end-of-life care in Colorado have strong feelings about the direction and activities of a Colorado center, any planning activities related to the development of a center or related projects should be allowed to proceed slowly and deliberately. It is critical that whatever time is needed should be taken to allow for the development of trust and respect among interested parties and for reaching true consensus as to how to proceed with mutually agreed upon goals. This is necessary in order to develop a cost-effective plan of action that has broad community support.

Appendices

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APPENDIX A

Centers and Institutes for End-of-Life and Palliative Care^{*}

Center	Location
Center for Ethics in Health Care, Oregon Health and Science University	Portland, Oregon
The Center for Excellence in End-of-Life Education, Research and Practice	Cheektowaga, New York (Buffalo area)
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	Tampa, Florida
Center for Palliative Care, Harvard University	Cambridge, Massachusetts
The Center for Palliative Care Studies at San Diego Hospice	San Diego, California
Center to Advance Palliative Care (CAPC), Mt. Sinai School of Medicine, NY	New York City, New York
Duke Institute on Care at the End of Life, Duke University Divinity School	Durham, North Carolina
The Hospice Institute of the Florida Suncoast	Largo, Florida (Tampa-St. Petersburg area)
The Institute, and Resource Center, for Education and Research in Pain and Palliative Care, Department of Pain Management & Palliative Care, Beth Israel Medical Center	New York City, New York
Maggie Allessee Center for Quality of Life, Hospice of Michigan	Detroit, Michigan
Midwest Bioethics Center	Kansas City, Missouri
The Practical Ethics Center, The University of Montana—houses The Robert Wood Johnson Foundation National Program Office for Promoting Excellence in End-of-Life Care	Missoula, Montana
University of Alabama Center for Palliative Care	Birmingham, Alabama

** This does not purport to be a complete list of centers. Rather it includes those centers that were easily identified via an Internet search and/or were recommended as programs to look at by directors of several of the more well known centers.*

APPENDIX B

People Who Were Interviewed, Filled Out a Written Survey or Provided Information for the Study

1. Interviewees Representing Colorado Consumer Groups

Nathan Byrd, Pastor
People's Presbyterian ¹

Danica Delgado, Family Service Coordinator
Huntington's Disease Society of America and
Colorado Neurological Institute

Dr. Bernard F. Gipson, Sr., MD (retired)
New Hope Baptist Church Health Ministry ³

Teresa Gonzales, Health Technician
Clinica Campesina ²

Emma Jackson, RN ¹
Health Coordinator Congregational Nurse
Zion Baptist Church and
Metro Denver Black Church Initiative

Lucille Johnson, Associate Director
Metro Denver Black Church Initiative ¹

Grant Jones, Executive Director
Metro Denver Black Church Initiative ¹

Mark Larson, State Representative, Cortez
Colorado General Assembly

Linda Mitchell, President & CEO
Alzheimer's Association, Rocky Mtn Chapter

Eleonor Montour
Referral Case Manager ²
Clinica Campesina

Vada H. Patterson, Assistant Pastor
Macedonia Baptist Church ¹

Rev. James Peters, Pastor ¹
New Hope Baptist Church

Ellen Stuart Roberts
Estate planning attorney and
Vice Chair, Board of Mercy Medical Center of
Durango, Colorado

Naomi Sullivan, Executive Director
QuaLife Wellness Community

Mella Dee Warren ¹
Congregational Nurse
Zion Baptist Church & Metro Denver Black
Church Initiative

Henry D. Wharton, Deacon
Rising Star MBC ¹

continued

¹ This person participated in a group interview of people associated with the Metro Denver Black Church Initiative that was held October 24, 2002. In the report, the input of those who were part of the group interview is reported as a single response, as group interview participants were not polled separately but rather commented as a group. Special thanks to Grant Jones, Executive Director of the Initiative, for pulling together people from his organization to be interviewed for this study.

² Eleonor Montour and Teresa Gonzales were interviewed together on October 25, 2002, concerning the interests and concerns of Hispanic patients and families. In the report, their input is reported as a single response, as they were not polled separately but rather commented together.

³ Dr. Gipson participated in the Metro Denver Black Church Initiative group interview and also filled out a written survey. His written survey answers are reported separately from those who participated in the group interview.

2. Colorado Hospice Director Survey Respondents

Corinne Ablin, Director
Porter Hospice & Hospice of Peace, Denver

Michelle Appenzeller, Nurse Executive
Outpatient Services—Home Health/Hospice
Mercy Medical Center, Durango

Pat Archer, Director
Exempla Lutheran Hospice, Wheatridge

Martha Barton, President & CEO ⁴
Pikes Peak Hospice & Palliative Care
Colorado Springs

Jan Beznidenhout, President & CEO
Namaste Comfort Care, Denver

Lois Booth, CEO
Hospice del Valle, Alamosa

Al Canner, Executive Director
Colorado Hospice Organization, Boulder ⁴

Marsha R. DiRienzo, Administrator
Bristlecone Health Services, Inc., Frisco

Joni Fair, President & CEO
Sangre de Cristo Hospice, Pueblo

Linda Gaetani, Director
VNA Hospice at Home, Denver

Ruth H. Lindstedt, Director
Estes Park Home Care & Hospice
Estes Park

Joleen Schneider, Executive Director
Prospect Homecare Hospice, Woodland Park

Darla Schueth, Executive Director
Hospice of Boulder County, Lafayette

Bev Sloan, President & CEO ⁴
Hospice of Metro Denver, Denver

Mary Ann Turner, RN, Director
Lamar Area Hospice, Lamar

Cathy Wagner, Executive Director
Life Source Hospice & Palliative Care, Lakewood

Fr. Peter B. Wellish, CEO & Exec. Director
Hospice of St. John, Lakewood

Christy Whitney, RN, MS, President & CEO ⁴
Hospice & Palliative Care of Western Colorado
Grand Junction

3. Other Knowledgeable Colorado Interviewees

Pat Crawford, RN, MSN, Coordinator
Palliative Care Initiatives, Centura Health ⁵

Nancy English, RN, PhD, APN
Project Faculty, School of Nursing, UCHSC &
Palliative Care Nurse, Children's Hospital

Dr. Glenn Gade, MD, Geriatrician & Operations
Chief, Medical Subspecialties
Kaiser Permanente

Beth Irtz, RN, NHA, Administrator
Clear Creek Care Center, Westminster

Marcia Lattanzi-Licht, MA, RN, LPC
Lattanzi-Licht Associates (expert in hospice & end-
of-life issues), Boulder

Linda Lenander, Director
Clinical Social Work Department
Denver Health

Larry Lewis, RN, MSN, Director
Senior Services, Parkview Medical Center

Anita Sanborn, consultant working with the
Bioethics Center, UCHSC

continued

⁴ This person filled out a survey form and also provided additional information in an interview with Yondorf & Associates.

⁵ Pat Crawford and Beth Pfalmer were interviewed together on October 23, 2002. In the report, their input was reported as a single response, as they were not polled separately but rather commented together.

3. Other Interviewees (cont'd)

Dr. Andrew S. Kraft, MD, Head
Division of Medical Oncology
University of Colorado Cancer Center, UCHSC

Dr. Robert S. Schwartz, MD, Head
Division of Geriatric Medicine, UCHSC

Dr. Jean Kutner, MD, MSPH
Associate Professor, Division of General Internal
Medicine, UCHSC & Director, Population-based
Palliative Care Research Network (PoPCRN)

Dr. Felicia Stonedale, MD
Palliative Care Partners, Alamosa

Mark Yarborough, PhD, Director
Center for Bioethics & Humanities, UCHSC

Beth Pfalmer, Manager⁵
Palliative Care Initiatives, Centura Health

Note: UCHSC stands for University of Colorado Health Sciences Center.

4. Staff from Centers in Other States Who Were Interviewed or Provided Information

The Center for Excellence in End-of-Life Education, Research and Practice, Buffalo, NY

J. Donald Schumacher
President & CEO

Judith A. Skretny
Vice President

Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida

Kathy Egan⁶
Community Director

Dr. Susan McMillan,
Professor of Nursing & a co-founder of the Center

Dr. Ronald Schonwetter⁶
Academic Director

The Center for Palliative Studies at San Diego Hospice, CA

Dr. Frank Ferris⁶
Medical Director of Palliative Care Standards &
Outcome Measures

Robin McGowan
Executive Assistant to the CEO

Center to Advance Palliative Care at the Mt. Sinai School of Medicine, NY

Carol E. Sieger, JD
Deputy Director

The Hospice Institute of the Florida Suncoast

Kathy Egan⁶
Director

Sandra Lambis
Executive Secretary to the President & CEO of
The Hospice of the Florida Suncoast

Susan Bruno
Director of Outreach

Pat Kantner
Assistant to the Director

continued

⁶ Participated in in-depth interview with Yondorf & Associates.

4. Staff from Centers in Other States (cont'd)

Maggie Allessee Center for Quality of Life, MI

Greg Grabowski
Senior Vice President for Research & Development,
Head of Community Relations, Hospice of Mich.

Angela Harrison
Executive Secretary to the Chief Financial Officer,
Hospice of Michigan

Bob Cayhill
Chief Financial Officer, Hospice of Michigan

Barbara Pallazolo
Corporate Public Relations Director

Midwest Bioethics Center, MO

Myra Christopher⁶
President and CEO

5. People Who Provided Additional Information

Carol Breslau
Senior Program Officer
The Colorado Trust

Judy Hutchison
Former Executive Director
Colorado Collaboration on End-of-Life Care

Susan Fox (Buchanan)
Former Executive Director
Colorado Collective for Medical Decisions

APPENDIX C

Need for and Possible Activities of a
Colorado Center for End-of-Life and Palliative Care

Community Leader Survey

Directions: Rose Community Foundation and Bonfils-Stanton Foundation have contracted with Yondorf & Associates to do a feasibility study. The purpose of the study is to determine what the major needs are in Colorado related to end-of-life care, and whether creation of a Colorado Center for End-of-Life and Palliative Care is the best way to meet those needs.⁷ As part of the study, we are surveying knowledgeable community leaders to solicit their input. Please take a few minutes to fill out this survey. All responses will be reported anonymously. **If you have any questions**, contact Barbara Yondorf at 303/355-8817 (yondorf@usa.net). Surveys should be returned by regular mail, e-mail or fax no later than **November 6, 2002** to:

Barbara Yondorf, Yondorf & Associates
2211 Clermont Street
Denver, CO 80207

Tel. 303-355-8817
Fax 425-962-2616
E-mail: yondorf@usa.net

Part A. Community Leader Information

Name of person filling out this survey: _____ Title: _____
Organization: _____ Phone number: _____ / _____
Address: _____ E-mail address: _____
_____ Profession: _____
Date: _____ In-person interview: ___ Mailed survey: ___

Part B. Survey Questions

2. What do you see as the **three most critical needs** with respect to establishing and maintaining a high quality end-of-life care system in Colorado and advancing the hospice concept of care? (Examples might include better training of physicians, improved collaboration at the community level, more public education about palliative care, etc.) Please list in priority order.

(1)

(2)

(3)

⁷ "Palliative care" refers to the active, interdisciplinary comfort care of individuals whose condition may not be responsive to curative treatment. It focuses on aggressive control of pain and other physical symptoms, and the emotional, social and spiritual priorities of the patient and family.

3. If you were providing **advice to a health care foundation** interested in end-of-life care, what would you tell them is **the best way to meet the needs you identified in the previous question**? What kind of endeavor or activity should they fund?

4. Currently, **what national, state and local resources do you turn to** for assistance with end-of-life or palliative care questions? (Please list the major resources and the type of information you get from each of them.)

Resource

Type of Information

5. (a) There has been some discussion about creating a Center for End-of-Life and Palliative Care in Colorado that would work with communities and health professionals to improve end-of life care. How would you **assess the need for such a center**? (Please check one and explain.)

Definitely needed because _____

Needed but only if _____

There may be a need for a center but other activities/projects have a much higher priority for me, such as _____

Not needed because _____

- (b) If you checked "Definitely needed" or "Might be a good idea," **what important difference do you think a center would make?**

6. If Colorado were to establish a center, which of the following do you think should be the **Center's three highest priorities**? (Check no more than three.)

Providing clinical advice to palliative care providers.

Disseminating best practices information to providers and the public.

Facilitating collaborative projects, especially at the community level, to improve end-of-life care.

Focusing on special populations (e.g., adolescents, people with developmental disabilities, etc.) and examining ways to improve end-of-life care for them.

Improving and enhancing training of health care professionals on end-of-life care.

Assisting the public and providers to link up with appropriate resources to meet their needs.

Working to improve access to palliative care.

Conducting and disseminating research on palliative and hospice care financing, reimbursement, and improved models of end-of-life and palliative care.

Advocating for end-of-life and palliative care issues.

Fostering better two-way communication between academia and the people who are providing end-of-life and palliative care in the community.

Promoting an ongoing dialogue about ethical, legal and moral issues related to end-of-life care.

Other. Please specify:

7. Who do you think should be the prime audience(s) for a Colorado End-of-Life and Palliative Care Center if one is created? (Check no more than **three**.)

- Physicians, nurses, and social workers
- Hospices and hospitals
- Nursing homes and home health providers
- Consumer health and health advocacy groups
- Academic programs that train health professionals
- Patients and families
- Colorado public policymakers
- General public
- Media
- Other? Please specify:

8. (a) If a Colorado Center for End-of-Life and Palliative Care is established, where should it be housed? (Check **one** and explain your answer below.)

- At the **University of Colorado Health Sciences Center (UCHSC)** as part of the **Center for Bioethics and Humanities**.
- At some **other academic institution** or elsewhere at UCHSC, such as: _____.
- As part of an existing hospice or hospital program or health services network, such as: _____.
- As part of the **Colorado Hospice Organization**.
- In some **other existing, nonprofit organization** or agency, such as: _____.
- In a **freestanding nonprofit** created just for this purpose.
- Other?** Please explain:

(b) What were your **reasons for making the choice that you did?**

9. What **types of people do you think should serve on the board** of a Colorado Center for End-of-Life and Palliative Care if one is created?

10. Do you think that the organization for which you work would be willing to **provide funding and/or staff resources to help ensure the sustainability of a Center** if one were created? (Monetary contributions could be in the form of dues, fees charged for certain services, a nominal annual fee to have access to the services of the Center, or in some other form.)

- Yes.** Please explain:
- No.** Please explain:

11. Do you have any **other comments, concerns or suggestions?**

Thank you. Please return this survey no later than November 6, 2002 to: Barbara Yondorf, Yondorf & Associates, 2211 Clermont Street, Denver, Colorado 80207 (Fax: 425-962-2616. E-mail: yondorf@usa.net).

You will automatically receive a copy of the survey results when they have been compiled.

APPENDIX D

**Detailed Informational Charts
For Seven Centers In Other States**

The Center for Excellence in End-of-Life Education, Research and Practice (Buffalo, NY)	A-11
Center for Hospice, Palliative Care and End-of-Life Studies at University of South Fla.	A-14
The Center for Palliative Studies at San Diego Hospice (CA)	A-18
Center to Advance Palliative Care (CAPC), Mount Sinai School of Medicine, NY	A-22
The Hospice Institute of the Florida Suncoast	A-25
Maggie Allessee Center for Quality of Life, Hospice of Michigan	A-29
Midwest Bioethics Center (MO)	A-33

THE CENTER FOR EXCELLENCE IN END-OF-LIFE EDUCATION, RESEARCH AND PRACTICE (BUFFALO, NY)

The Center for Excellence in End-of-Life Education, Research and Practice	
Address & Phone	<p>The Center for Excellence in End-of-Life Education, Research and Practice 225 Como Park Boulevard Cheektowaga, NY 14227-1480</p> <p>Tel. (716) 686-1900 E-mail: info@palliativecare.org</p>
Website	<p>[The Center's website is not yet running. However information about the Center can be found at http://www.palliativecare.org/news_display.aspx?NEWS_ITEM_ID=4]</p>
Director	<p>Judith A. Skretny, MA. (Skretny is also a Vice President of The Center for Hospice & Palliative Care, of which The Center for Excellence is a part).</p>
Type of entity	<p>The Center for Excellence is a program of The Center for Hospice & Palliative Care, a nonprofit organization serving the Buffalo, New York, area.* The Center for Excellence was formally established in 2002 but has unofficially been in operation for two years.</p> <p><i>* The Center for Hospice & Palliative Care is also the parent organization of Hospice Buffalo, Home Care Buffalo, Kresge Residence, Life Transitions Center, Caring Hearts Home Care, the Hospice Foundation of WNY and CMI Education Institute. It provides services that enhance the comfort and quality of life for those experiencing the impact of serious illness and loss. More than 500 patients a day are cared for by The Center for Hospice and Palliative Care.</i></p>
Mission	<p><u>Purpose:</u>*</p> <ul style="list-style-type: none"> • To create an innovative and enduring national template for exemplary end-of-life education, research and practice, and • To improve the way in which end of life care is presented to our future practitioners and practiced by our community's health care providers <p><i>* Based on news release announcing the formation of the Center, May 30, 2002</i></p>
Primary audience(s)	<ul style="list-style-type: none"> • Academic medical programs • Medical students and other health care professionals in training • Community health providers • Lay community • Those interested in end-of-life research
Major activities	<p>Current and anticipated activities:</p> <ul style="list-style-type: none"> • Training and education. The Center will provide training and educational activities to teach palliative care medicine to health care professionals at the

The Center for Excellence, Buffalo, NY (p. 2)	
Major activities (cont'd)	<p>undergraduate, graduate and postgraduate levels. The training will be accomplished in a variety of ways including: didactic presentations, grand rounds, formal elective rotations, and continuing education conferences that embody the whole range of issues pertinent to care at the end-of-life.</p> <ul style="list-style-type: none"> • Development of interdisciplinary curricula. The project is meant to construct interdisciplinary curricula for all professionals who render palliative care to the community. As part of this initiative, Hospice will work with the pre-clinical and clinical faculty of the S.U.N.Y. Buffalo Schools of Medicine, Dentistry, Pharmacy, Nursing, Social Work and Health Related Professions, as well as with regional colleges. • Community education. The Center will also offer educational programs for the lay community, including care giving issues, self-advocacy and advance directives.
Areas of emphasis	<ul style="list-style-type: none"> • End-of-life care • Palliative care
Recent publications, activities	<p><u>Research:</u></p> <ul style="list-style-type: none"> • Research Project – “Hospice Care Utilization by Medical Oncologists in Cancer Centers” • Research Project – “At the Eleventh Hour: Psychosocial Factors that Contribute to Delayed Hospice Care for Terminally Ill Older Adults” • Study on ritalin <p><u>Education:</u></p> <p>Internal:</p> <ul style="list-style-type: none"> • Depression In-service • Cancer Series – In process <p>External:</p> <ul style="list-style-type: none"> • EPEC (Education for Physicians on End-of-Life Care) training • Training of local emergency medical technicians • Program on Medicine and Spirituality. • Development of a certificate program in hospice and palliative care • End of Life Research Interest Group--plans for two programs in 2003 • Curriculum development with SUNY Buffalo Schools of Medicine, Nursing, Social Work, Pharmacy, Dentistry and Health Related professions • Faith and Medicine Elective – School of Medicine/Family Medicine • Third Year Medical Students – Full day experience on CHPC campus (6x/year) <p><u>Sample national working relationships, 2003:</u></p> <ul style="list-style-type: none"> • RWJ American College of Surgeons Surgical Palliative Care Workgroup • RWJ Surgical Residency Training Program Initiative • National Cancer Centers Network Palliative Care Workgroup
Board—size, membership, who appoints	<p>The Center for Excellence has an Advisory Committee, which meets quarterly. Currently the Advisory Committee consists of 6 members, although it is expected to grow in size:</p> <p style="text-align: right;"><i>continued</i></p>

The Center for Excellence, Buffalo, NY (p. 2)	
Board—size, membership, who appoints (cont'd)	<p>2 physicians, Chair of the Nursing Department at a local college A retired professor specializing in medical ethics A person with a doctorate in nursing A clergy person</p>
Director's background	<p>Judith Skretny, MA, has an academic background in religion and chemistry. She has worked with the Center for Hospice and Palliative Care since 1982, including serving as Vice President for the Life Transitions Center (pastoral care, bereavement.).</p>
Staff size and titles	<p>Currently 2.5 FTE:</p> <ul style="list-style-type: none"> 1.0 Director 0.3 Medical Director 0.2 Hospice Medical Director 1.0 Administrative Assistant <p>Will soon hire a full-time Nurse Researcher to oversee outside research projects and help develop internal projects.</p>
Annual budget and breakdown	<p>[The Center did not supply its budget.]</p>
Main funding sources	<ul style="list-style-type: none"> • John R. Oishei Foundation—three-year grant, totaling \$518,400 • Other grants <p>The Center for Excellence also receives a great deal of in-kind support from its parent organization, The Center for Hospice and Palliative Care.</p> <p><i>Note: The concept to develop the Center for Excellence was made possible through a \$60,000 start-up grant provided by the Western New York Foundation to The Center for Hospice & Palliative Care in 2000.</i></p>
Annual report	<p>Does not yet exist.</p>
Additional background information	<p>The Center for Excellence is housed within The Center for Hospice & Palliative Care. This Center for Excellence was established in 2002, with a \$518,400 grant for three years. The John R. Oishei Foundation, the grantor, is a Buffalo philanthropic organization.</p>
Sources of information for this chart	<ul style="list-style-type: none"> • Judith A. Skretny – Vice President, The Center for Excellence in End-of-Life Education, Research and Practice (phone interview, November 2002) • J. Donald Schumacher, President, CEO, The Center for Excellence in End-of-Life Education, Research and Practice (in-person interview, October 10, 2002) • The Center for Excellence's website: http://www.palliativecare

CENTER FOR HOSPICE, PALLIATIVE CARE & END-OF-LIFE STUDIES AT UNIVERSITY OF SOUTH FLORIDA

Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida	
Address & Phone	<p>Center for Hospice, Palliative Care and End-of-Life Studies at University of South Florida c/o Ronald Schonwetter, MD University of South Florida College of Medicine Department of Internal Medicine Division of Geriatric Medicine 12901 Bruce B. Downs Blvd., Box 19 Tampa, Florida 33612</p> <p>(813) 974-2460</p>
Website	<p>http://65.32.12.70:777/ and http://hsc.usf.edu/PUBAFF/hot/endoflife.html</p>
Director	<p>Academic Director: Dr. Ronald Schonwetter, MD Community Director: Kathy Egan, Director of The Hospice Institute of the Florida Suncoast</p>
Type of entity	<p>The Center is a partnership between the University of South Florida and local hospices. Based at the University's Colleges of Medicine, Nursing and the College of Arts and Sciences, it is an interdisciplinary research center.</p> <p>In many respects the Center functions as a "virtual" center, with no specific, central physical location for all of its staff or activities. A substantial amount of the Center's work is done by diverse research faculty with interests in palliative care and end-of-life studies who are in various departments at the University.</p> <p>The role of Kathy Egan as Community Director of the Center and of the other hospices associated with Center is to encourage the Center to collaborate and partner with community institutions on projects that are consistent with the needs and interests of community providers. They also provide a kind of research laboratory for the Center's faculty, in the form of access to patients, charts, etc., with prior approval.</p> <p>Although the Center was formally opened in 2002, its characteristic coordinating functions have been occurring informally for 2-4 years.</p>
Mission	<p><u>Mission:</u></p> <p>"The mission of the Center is to optimize care and systems of care for patients and families affected by advanced non-curable diseases by generating new knowledge through interdisciplinary research, using that knowledge to educate health and human service professionals, and influencing public policy that supports quality end of life care."</p>

**Center for Hospice, Palliative Care and End-of-Life Studies at
University of South Florida (p. 2)**

<p>Mission (cont'd)</p>	<p><u>Goals</u> are to:</p> <ul style="list-style-type: none"> • Assist researchers to explore and develop researchable ideas that may be pursued through intramural or extramural funding; • Link researchers from varied disciplines whose research and teaching would be complemented by working together on important research questions related to palliative care and end of life issues. • Seek opportunities to develop and test relevant measurement tools. • Develop a uniform data base at multiple sites to foster multicenter trials. • Participate in research utilization and dissemination through presentations, publications, and classroom teaching. • Involve learners at all levels in the activities of the Center as appropriate. • Enhance classroom and continuing education programs related to palliative care and end of life issues.”
<p>Primary audience(s)</p>	<ul style="list-style-type: none"> • Health care provider community • Graduate students • Academic community and other end-of-life care researchers
<p>Major activities</p>	<ul style="list-style-type: none"> • Research • Education • Collaborative activities among researchers, clinicians, and the community.
<p>Areas of emphasis</p>	<p>There is not yet a center-wide agenda. The interests of researchers drive the work, although the center helps the research to be inter-disciplinary.</p> <p>According to the Center’s website, “Research on quality of life may include but is not limited to:</p> <ul style="list-style-type: none"> • End of life issues for both patients and caregivers • Palliative care issues • Symptom management in chronic illness and end of life care • Rehabilitation issues in quality of life”
<p>Recent publications, activities</p>	<p>These projects were developed by faculty members associated with the Center:</p> <ul style="list-style-type: none"> • A project to evaluate whether teaching new problem-solving skills to family members caring for dying cancer patients in their homes translates into improved quality of life for the patients and their caregivers. This project is being underwritten with a \$1.25 million Caregivers Intervention grant from the National Cancer Institute and the National Institute for Nursing Research. • A study of falls in hospice patients, for the Veterans Administration. • A study of depression at the end of life, funded with a \$925,000 grant from the National Institute for Nursing Research.

**Center for Hospice, Palliative Care and End-of-Life Studies at
University of South Florida (p. 3)**

Recent publications, activities (cont'd)	<ul style="list-style-type: none"> • Development of an interdisciplinary certificate program in palliative care and end-of-life studies that will be open to all graduate students and health professionals in the community. The program is co-sponsored by the College of Nursing and the Department of Gerontology.
Board—size, membership, who appoints	<p>12-member Executive Committee chaired by Schonwetter. Half of the committee are University of South Florida faculty members from the various interested departments. The other half are community members, such as hospice representatives.</p>
Director's background	<p><u>Academic Director, Dr. Ronald Schonwetter</u> has an MD in Internal Medicine, is certified in Hospice and Palliative Medicine, and specializes in Geriatric Medicine. He has served as a medical director for several hospices, a skilled nursing facility and a nursing center. In 1994, he joined the faculty of the Division of Geriatric Medicine, Department of Internal Medicine, University of South Florida (USF) College of Medicine. Dr. Schonwetter is currently Director of the Geriatric Medicine Program at the USF College of Medicine.</p> <p><u>Community Director, Kathy Egan of The Hospice of the Florida Suncoast</u> has a BS in Nursing and an MA in Education and Public Health. Her background includes substantial experience in health care provision, administration and education. Egan is Director of The Hospice Institute of the Florida Suncoast (which is described elsewhere in this report).</p>
Staff size and titles	<p>Currently the Center's budget directly supports 0.35 FTE:</p> <p style="padding-left: 40px;">0.25 Faculty – writing grants to establish and develop the Center 0.35 Administrative support – coordinating meetings, dispersing checks, taking minutes at Center meetings, arranging for audio-visual equipment, etc.</p> <p>The Center is also considering hiring someone with methodological and statistical expertise.</p> <p>All of the other researchers associated with Center are not employees of the Center as such. Instead, they are funded through their own departments, in many cases with grants to do research related to end-of-life and palliative care.</p>
Annual budget and breakdown	<p>Not provided by the Center. However, an analysis of funding sources suggests its currently about \$200,000. (See "Main funding sources.")</p>
Main funding sources	<p>\$256,000 to be spent over the first three years. Sources:</p> <p style="padding-left: 40px;">\$100,000 - LifePath Hospice and Palliative Care \$100,000 - The Hospice of the Florida Suncoast \$ 56,000 - H. Lee Moffitt Cancer Center and Research Institute</p> <p>The Center just received notice of an additional \$100,000 per year from the University's Health Sciences Center (of which the Center for Hospice, Palliative Care and End-of-Life Studies is a part).</p>

**Center for Hospice, Palliative Care and End-of-Life Studies at
University of South Florida (p. 4)**

Annual report	None
Additional background information	<ul style="list-style-type: none"> • Faculty and researchers associated with the Center for Hospice, Palliative Care and End-of-Life Studies hold regular meetings with community representatives to review and get input on the Center's activities. • The Center makes available to University researchers planning grants of up to up to \$5,000 to develop preliminary data to apply for grants related to end-of-live and palliative care • Graduate Research Assistants can get funding from the Center to develop a project with a mentor in return for providing one-half day per week of work at a local hospice. • "Think tanks" have been created at various venues for interest groups to address such questions as "What would be a good research agenda for palliative care?"
Sources of information for this form	<ul style="list-style-type: none"> • Website for the Center: http://65.32.12.70:777/ • Dr. Ronald Schonwetter, academic director. • Dr. Susan McMillan, Professor of Nursing and a co-founder of the Center • Curriculum vita for Ronald Schonwetter. Website: http://65.32.12.70:777/People/ronald_schonwetter,_md_-_cv.htm

THE CENTER FOR PALLIATIVE STUDIES AT SAN DIEGO HOSPICE (CA)

The Center for Palliative Studies at San Diego Hospice	
Address & Phone	<p>The Center for Palliative Studies at San Diego Hospice 4311 Third Avenue San Diego, California 92103</p> <p>Tel. (619) 688-1600</p>
Website	<p>http://www.grief.org/cps.htm</p>
Director	<p>Dr. Charles F. von Gunten, MD PhD FACP, Medical Director, Center for Palliative Studies, Associate Clinical Professor of Medicine, UCSD School of Medicine</p>
Type of entity	<p>The Center for Palliative Care Studies is a private nonprofit under the umbrella of the San Diego Hospice Corporation.* The Center was established in January 1988 with a grant from the W.M. Keck Foundation. The Center is a designated teaching affiliate of the University of California at San Diego, San Diego State University, the University of San Diego, and the Pacific College of Oriental Medicine.</p> <p><i>* San Diego Hospice was incorporated in 1977 as an academic hospice. The hospice cares for more than 3,500 patients annually. It has over 500 staff and 500 volunteers.</i></p>
Mission	<p><u>Purpose:</u> To coordinate and foster education, research and advocacy for hospice and palliative care.</p> <p><u>Tag line:</u> "Center for Palliative Care Studies at San Diego Hospice--Advancing the Art and Science of Comfort and Quality of Life"</p>
Primary audience(s)	<p>Diverse, depending upon the work. Among others, includes:</p> <ul style="list-style-type: none"> • Health care professionals and institutions • Researchers • Students • Government agencies • Foundations
Major activities	<p><u>Education and Professional Training:</u></p> <p>CPS faculty offer educational programs to both healthcare professionals in training and those in practice, as well as to the larger community. Among those offered training are 65 medical residents and fellows from Family Medicine, Geriatrics, Internal Medicine, Oncology and Pain Management; 225</p>

The Center for Palliative Studies at San Diego Hospice (p. 2)

<p>Major activities (cont'd)</p>	<p>medical students, 90 nursing students, 27 bereavement counseling interns, 12 dietitian interns, and others.</p> <ul style="list-style-type: none"> • The education programs for health care professionals in practice, include: continuing education courses, conferences and information services, a visitors program for professionals, and a visiting scholar program. • The Center's Community Education Program provides information about palliative care and the Center's programs and services to the community at large through seminars, a speakers' bureau, tours, information booths at community events and health fairs, and a community education library of brochures and videos for public use. The Center also maintains a website as a portal to hospice and palliative care information on the Internet. (http://www.cpsonlyin.info). <p><u>Research:</u></p> <ul style="list-style-type: none"> • The Center conducts research on a wide range of topics related to hospice and palliative care. • To oversee and review research conducted by The Center for Palliative Studies, the Center maintains its own Institutional Review Board.
<p>Areas of emphasis</p>	<ul style="list-style-type: none"> • Pain relief • Symptom control • Quality of life • Severity of illness • Cost effectiveness of treatments • Development of delivery systems • Bereavement
<p>Recent publications, activities</p>	<p><u>Selected Sample of 2002 Publications by faculty of the Center for Palliative Studies:</u></p> <ul style="list-style-type: none"> • Emanuel LL, Ferris FD, von Gunten CF. EPEC. "Education for Physicians on End-of-Life Care." American Journal of Hospice and Palliative Care 2002;19(1):17; discussion 17-8. (Letter). • Ferris FD, et al. "A model to guide hospice palliative care." Ottawa, ON: Canadian Hospice Palliative Care Association, March 2002. • Frederich ME, Strong R. "Physician-nurse conflict: can nurses refuse to carry out doctor's orders?" Journal of Palliative Medicine 2002;5(1):155-158. • Evans W, Bluestein H. Herbst L, von Gunten CF. "Evaluation of a required hospice rotation for 3rd year medical students." American Academy of Hospice and Palliative Medicine. Journal of Palliative Medicine 2002;6(1):201. • Kronenberg R, Cox MC, Naco GC, von Gunten CF. "Intravenous lidocaine for intractable pain—a retrospective chart review." American Academy of Hospice and Palliative Medicine. Journal of Palliative Medicine 2002;6(1):214.

The Center for Palliative Studies at San Diego Hospice (p. 3)

<p>Recent publications, activities (cont'd)</p>	<ul style="list-style-type: none"> • Davies B, Brenner P, Orloff S, Sumner L, Worden W. "Addressing spirituality in pediatric hospice and palliative care." Journal of Palliative Care 2002;18(1):59-67. • Sumner L. "Core Curriculum for the Generalist Hospice & Palliative Nurse: End of Life Care for the Child & Family." In: Hospice and Palliative Nurses Association. End of Life Care for the Child & Family. Dubuque, Iowa: Kendall-Hunt Publisher, 2002:205-23. <p><u>Selected Sample of Courses Offered by the Center:</u></p> <ul style="list-style-type: none"> • Palliative Medicine Fellowship • Hospice/Palliative Medicine Clerkship • Ethics • Education for Physicians in End-of-Life Care (EPEC) • Clinical Practicum in Hospice Pharmacy • Clinical Practicum in Hospice Chaplaincy • Grief and Bereavement Counseling • Visiting Scholar Program
<p>Board size, membership, who appoints</p>	<p>None. However the Center does have various committees, for example the Committee on Education.</p>
<p>Director's background</p>	<p>Dr. Charles F. von Gunten has an MD and a PhD in biochemistry. He did his internship and residency training in internal medicine, followed by subspecialty training in hematology/oncology. Before heading up the Center for Palliative Care Studies, he was an Assistant Professor of Medicine at Northwestern Medical School, where he directed programs in hospice and palliative care, education, and research. He currently holds the academic rank of Associate Clinical Professor of Medicine, University of California, San Diego.</p>
<p>Staff size and titles</p>	<p>The Center's website lists 28 faculty and staff (not including members of the Center's Institutional Review Board), 8 of whom have MDs: *</p> <ul style="list-style-type: none"> • Assistant, Education • Associate Manager, Education • Chair, Institutional Review Board (IRB) • 4 Clinical Medical Directors • Coordinator, Education Programs • Coordinators, Research Programs • Director Emerita of San Diego Hospice • Director Bereavement and Volunteers • Director Hospice Homecare • Director of Inpatient Care Center • Director, Palliative Home Healthcare • Director, Community Education • Director, Children's Program

The Center for Palliative Studies at San Diego Hospice (p. 4)

<p>Staff size and titles (cont'd)</p>	<ul style="list-style-type: none"> • 2 Family Nurse Practitioners • Fundraising and Development Director • Founding Director, Center for Palliative Studies • Medical Director, Palliative Care Standards / Outcome Measures • Medical Director, Palliative Home Healthcare • Medical Director, Long-term Care Services • Medical Director, Inpatient Care Center and Integrative Medicine Program • Medical Director, Pediatric Services • Medical Director, Center for Palliative Studies • Vice President, Clinical Affairs • Vice President, Medical Affairs <p><i>* Note: Yondorf & Associates was unable to determine how many FTE the Center has. Many of the faculty and staff hold other positions, for example with the San Diego Hospice or with the medical school.</i></p>
<p>Annual budget and breakdown</p>	<p>The Center's expenses totaled just a little over \$1 million in 2001.</p>
<p>Main funding sources</p>	<ul style="list-style-type: none"> • A variety of sustaining grants for education and research • A small endowment • Some support from the San Diego Hospice
<p>Annual report</p>	<p>None.</p>
<p>Additional background information</p>	<p>The Center for Palliative Studies at San Diego Hospice is responsible for professional education and research programs. It was established in January, 1988 by a grant from the W.M. Keck Foundation. The Center is a teaching and research affiliate of the University of California, San Diego, School of Medicine</p>
<p>Sources of information for this chart</p>	<ul style="list-style-type: none"> • Dr. Frank Ferris, Medical Director of Palliative Care Standards and Outcome Measures (phone interview , November 19, 2002) • Robin McGowan, Executive Assistant to the CEO (phone interview, October 8, 2002) • "Combined Financial Statements for San Diego Hospice Corporation and San Diego Hospice Foundation, Inc., December 31, 2001 and 2002," Grace, Lund and Tarkington LLP • "San Diego Hospice Annual Report 2002" • List of faculty publications, 2002. • Website

**CENTER TO ADVANCE PALLIATIVE CARE (CAPC),
MOUNT SINAI SCHOOL OF MEDICINE, NY**

Center to Advance Palliative Care at the Mount Sinai School of Medicine	
Address & Phone	Center to Advance Palliative Care (CAPC) The Mount Sinai School of Medicine 1255 5th Avenue, Suite C2 New York, NY 10029-6574 Tel. (212) 201-2670
Website	www.capc.org
Director	Diane Meier, MD, FACP, Director, Center to Advance Palliative Care, and Director, Hertzberg Palliative Care Institute, Mount Sinai School of Medicine
Type of entity	The nonprofit CAPC (referred to as “cap-C”) is a Robert Wood Johnson Foundation National Initiative with direction and technical assistance provided by Mount Sinai School of Medicine. The Center has a national focus. It was created November 1999.
Mission	“Our mission is to increase the availability of palliative care services in hospitals and other healthcare settings for people with life-threatening illnesses, their families and caregivers.”
Primary audience(s)	CAPC serves a broad constituency of providers and groups who are interested in setting up and or improving their hospital-based palliative care programs, including physicians, nurses, educators, policymakers, health researchers, payers, and, ultimately, patients and their families.
Major activities	<ul style="list-style-type: none"> • Provides support and technical assistance for hospital-based palliative care programs, ranging from business planning and financial projections to quality initiatives and outcome measures. • Sponsors regular regional and national meetings designed to provide a core curriculum for programs in planning or early stages of development.
Areas of emphasis	<p>CAPC’s focus is on hospital-based palliative care. However, it works closely with community-based hospices and is beginning to reach out to long-term care facilities. The program:</p> <ul style="list-style-type: none"> • Provides technical assistance and education • Conducts special studies • Provides networking and information resources

Center to Advance Palliative Care at the Mt. Sinai School of Medicine (p. 2)

<p>Recent publications, activities</p>	<p><u>Publications:</u></p> <ul style="list-style-type: none"> • “The Case for Hospital-Based Palliative Care” • “CAPC How to Manual” • “Planning a Hospital-Based Palliative Program: A Primer for Institutional Leaders” • “Palliative Care: An Opportunity for Medicare” • “Physician’s Survey: a Needs Assessment Tool to Build Support’ • “CAPC Marketing Tool” • “Impact of Palliative Care Education on Students” • “Hospital/Hospice Partnerships in Palliative Care” <p><u>Upcoming conference:</u></p> <ul style="list-style-type: none"> • “Planning, Funding and Sustaining a Hospital-Based Palliative Care Program: Tools and Strategies for Success,” February 27 – March 2, 2003, Philadelphia <p><u>Recent Conference (New Orleans) topics included:</u></p> <ul style="list-style-type: none"> • Module 1: Program Rationale and Needs Assessment • Module 2: Creating Compelling Business and Financial Plans • Module 3: Selecting an Organizational Model • Module 4: Quality "Start Up" Measures and Instruments • Module 5: Structuring Hospital-Hospice Partnerships • Module 6: Marketing a Palliative Care Program: Knowing Your Audiences and Developing Your Messages • Putting it all together • Session A: Medicare Payments to Physicians • Session C: Financing a Palliative Care Program • Session C: Medicare Payments to Physicians • Session D: Developing a Financial Plan
<p>Board—size, membership, who appoints</p>	<p>CAPC does not have a board. However, as mandated by the Robert Wood Johnson Foundation, CAPC does have a National Advisory Committee.</p>
<p>Director’s background</p>	<p>Dr. Diane Meier is Director of the Center to Advance Palliative Care. She is also Director of the Lilian and Benjamin Hertzberg Palliative Care Institute; Professor of Geriatrics and Internal Medicine; Catherine Gaisman Professor of Medical Ethics; and Chief of the Division of Geriatrics for the Department of Medicine at the Mount Sinai School of Medicine (NY). She received her BA from Oberlin College, and her MD from Northwestern University Medical School. She completed her residency and fellowship training at Oregon Health Sciences University in Portland. Dr. Meier has been on the faculty of the departments of Geriatrics and Medicine at Mount Sinai since 1983.</p>
<p>Staff size and titles</p>	<p>9 staff:</p> <ul style="list-style-type: none"> • Director • Deputy Director • Senior Project Director <p align="right"><i>continued</i></p>

Center to Advance Palliative Care at the Mt. Sinai School of Medicine (p. 3)

<p>Staff size and titles (cont'd)</p>	<ul style="list-style-type: none"> • Project Officer • Associate, Events & Communications person • Director of Communications • Program Associate • Administrative Assistant • Web Master <p>The Center also works with a number of consultants (MBA's, specialists in marketing, hospice liaisons, etc.).</p>
<p>Annual budget and breakdown</p>	<p>[CAPC did not provide a budget.]</p>
<p>Main funding sources</p>	<p>The Robert Wood Johnson Foundation</p>
<p>Annual report</p>	<p>None</p>
<p>Additional background information</p>	<p>---</p>
<p>Sources of information for this chart</p>	<ul style="list-style-type: none"> • Carol E. Sieger, JD, Deputy Director • Website

THE HOSPICE INSTITUTE OF THE FLORIDA SUNCOAST

The Hospice Institute of the Florida Suncoast	
Address & Phone	<p>The Hospice Institute of the Florida Suncoast 300 East Bay Drive Largo, Florida 33770-3770</p> <p>(727) 586-4432</p>
Website	<p>www.thehospice.org/inst.htm</p>
Director	<p>Kathy Egan, head of The Hospice Institute of the Florida Suncoast and Vice President of The Hospice of the Florida Suncoast.</p>
Type of entity	<p>The Hospice Institute is a division of The Hospice of the Florida Suncoast, which is a nonprofit, community-based hospice.* The Institute was created in 1993.</p> <p><i>* The Hospice of the Florida Suncoast was found in 1977 and is the largest nonprofit, community-based hospice in the world. It has a staff of 950 (including the staff of The Institute) and 2,7 00 volunteers. The Hospice provides provide care and support to 1,200 individuals and families every day.</i></p>
Mission	<p><u>Mission</u>: "The mission of The Hospice Institute of the Florida Suncoast is to:</p> <ul style="list-style-type: none"> • Provide communities, volunteers and professionals training, research, resources and education to improve end-of-life care; • Evaluate models to improve palliative and end-of-life care; and • Define and conduct clinical and organizational research to advance end-of-life practice and influence end-of-life public policy initiatives." <p><u>Vision</u>: "The leading center for end-of-life education, research and innovation."</p> <p><u>Goals</u>: "The Institute's goals are to innovate and share information, data, resources and models of care with other agencies to improve the service to those at the end of life."</p>
Primary audience(s)	<ul style="list-style-type: none"> • The Hospice of the Florida Suncoast • Other hospices • Hospitals • Health care systems • Social service systems • Academia
Major activities	<p>The Hospice Institute is a training, research and consulting center both for people living in Pinellas County and for those involved in end-of-life care across the country and internationally. Among its activities are the following:</p>

The Hospice Institute of the Florida Suncoast (p. 2)

<p>Major activities (cont'd)</p>	<p><u>Education and training:</u></p> <ul style="list-style-type: none"> • Conducts community training for lay and professional audiences on topics such as care giving skills, living with a chronic illness, advance directives. • Does internal training for many of the 950 staff and 2,700 volunteers of The Hospice of the Florida Suncoast . • Does external training and education for hospice workers outside The Hospice of the Florida Suncoast, on a contract basis, across the country. • Trains health and human service professionals on palliative care, ethical issues, pain and symptom relief, etc. • Works on curriculum development and administration • Maintains community resource centers/libraries at its service centers <p><u>Participation in research on end-of-life care:</u></p> <ul style="list-style-type: none"> • Facilitates partnerships between university researchers and the hospice(s), and its staff members. • Serves on local and national boards and committees that coordinate or make recommendations regarding research. <p><u>Consulting:</u></p> <ul style="list-style-type: none"> • Provides consultation services to help other health care systems on a variety of topics. • Provides Information for end-of-life service providers via trainings, consultations and from their services and products catalog. • Offers some of its services and publications nationally.
<p>Areas of emphasis</p>	<p>The Hospice Institute deals with all aspects of end-of-life care for all disciplines and for all types of caregivers. It also consults on hospice administrative issues. Examples of areas of expertise include:</p> <ul style="list-style-type: none"> • Pain and symptom relief • Ethical issues • Palliative care • Patient/family-directed quality end-of-life care • Caregiving skills • Hospice management (e.g., compliance and regulatory issues, fund development and management, strategic positions and planning, palliative care program development, public engagement, volunteer development and management, etc.)
<p>Recent publications, activities</p>	<p>Examples of the extensive activities in which The Hospice Institute is engaged are:</p> <p><u>Publications:</u></p> <ul style="list-style-type: none"> • Articles in the Journal of Hospice and Palliative Care Nursing and the American Journal of Nursing. • A chapter in the Textbook of Palliative Nursing, Oxford University Press. • “Building Access to End of Life Care: The Dance Between Community Awareness, Strategic Partnerships and Referral/Admission Management,” a manual. • “The Volunteer Coordinator Guideline Manual” • “Borrowed Pearls: A Hospice Spiritual Resource”

The Hospice Institute of the Florida Suncoast (p. 3)

<p>Recent publications, activities (cont'd)</p>	<p><u>Toolkits:</u></p> <ul style="list-style-type: none"> • “Lifetime Legacies: A Life Review Toolkit” • “Hospice Teen Volunteer Program Toolkit” <p><u>Training programs:</u></p> <ul style="list-style-type: none"> • “Advanced Hospice Accounting” • “Pain and Symptom Relief Primer” • “Documenting Quality End-of-Life Care and Assuring Compliance: A Comprehensive Staff and Volunteer Training Program” <p>The Hospice Institute also produces videos and audiotapes that it uses in its training programs and sells.</p>
<p>Board of Directors</p>	<p>The Hospice Institute has a 16 member consultative board. The consultative board includes academicians from a number of different disciplines that are involved in end-of-life and palliative care, and people from the community at large (e.g., hospital representatives, volunteers, attorneys, etc.).</p>
<p>Director’s background</p>	<p>Kathy Egan has BA in Nursing and an MA in Adult Education and Health. She has substantial and diverse experience in nursing, education, counseling and administration in medical and social service institutions. She has also done corporate training and set up several different programs. She joined The Hospice of the Florida Suncoast in 1989, initially as a patient care nurse. Later she worked on The Hospice’s education programs before helping to develop and run The Hospice Institute of the Florida Suncoast.</p>
<p>Staff size and titles</p>	<p>The Institute has 14 employees:</p> <ul style="list-style-type: none"> • Institute Director • 3 Program directors: of Outreach, Professional Development, and Research • 5 Coordinators: <ul style="list-style-type: none"> – 1 for Volunteers (the Institute has 40 volunteers working for it), – 2 for Nursing Training, – 1 for Psycho-social and spiritual – 1 for Caregivers and associates • 1 person who works as academic (student affiliation) liaison and does initial hospice training • 4 Administrative assistants <p>(The Institute also employs various other people for specific projects as needed.)</p>
<p>Annual budget and breakdown</p>	<p>\$1.25 million annual budget.</p>
<p>Main funding sources</p>	<ul style="list-style-type: none"> • 50% from: <p>Moneys from other divisions within The Hospice of the Florida Suncoast for services provided to those other divisions (primarily in-service training and educational programs)</p> <p align="right"><i>continued</i></p>

The Hospice Institute of the Florida Suncoast (p. 4)	
Main funding sources (cont'd)	<ul style="list-style-type: none"> • 50% from: <ul style="list-style-type: none"> - Grant funding (e.g., from the National Institutes of Health, Hartford Foundation, Administration on Aging, etc.) - Funding from the Hospice Foundation of the Florida Suncoast Foundation - Income and revenue (minimal) from consulting, training, selling products outside of The Hospice of the Florida Suncoast
Annual report	N/A –Institute’s activities subsumed under The Hospice’s report.
Additional background information	Among other things, The Hospice Institute has trained more than more than 950 service providers from across the country. The Institute has coordinated thousands of student affiliations and consulted with hundreds of providers seeking to enhance their care systems.
Sources of information for this chart	<ul style="list-style-type: none"> • Website • Kathy Egan, Director of the Institute (phone interview, November 12, 2002) • Susan Bruno, Director of Outreach (phone interview, November 12, 2002) • Sandra Lambis, Executive Secretary to the President and CEO of The Hospice of the Florida Suncoast (phone interview, October 2002) • Pat Kantner, Assistant to Kathy Egan (Phone interview, October 2002) • “2002 Services and Products Catalog” of The Hospice Institute of the Florida Suncoast

MAGGIE ALLESSEE CENTER FOR QUALITY OF LIFE, HOSPICE OF MICHIGAN

Maggie Allessee Center for Quality of Life	
Address & Phone	Maggie Allessee Center for Quality of Life Hospice of Michigan 400 Mack Avenue Detroit, Michigan 48201 (885) HOM-5656
Website	http://www.hom.org
Director	Dottie Deremo is President and CEO of the Hospice of Michigan and the Center for Quality of Life. However, in terms of day-to-day operations, Gregory Grabowski, Senior Vice President for Research and Development at the Hospice of Michigan, is responsible for the Center.
Type of entity	<p>The Center for Quality of Life is part of the Hospice of Michigan, which is a private, nonprofit corporation.* Formation of the Center was announced in October 2001 and made possible by a \$3 million individual donation from philanthropist Maggie Allessee. Prior to that time, staff of the Hospice of Michigan carried out a number of the activities that subsequently became housed in the new Center.</p> <p><i>* Hospice of Michigan was founded in 1994 with the merger of 10 hospices. In 2001, it served more than 7,000 patients in the 45 counties of the Lower Peninsula of Michigan. It has a staff of more than 650, including those who work for the Center for Quality of Life. Its annual budget (including the Center) is \$50 million.</i></p>
Mission	<p><u>Vision:</u> “The Maggie Allessee Center for Quality of Life will:</p> <ul style="list-style-type: none"> • Foster new ways of thinking about quality of life and death, and the wide variety of issues that people face at the end of life through collaborative approaches at the local, state and national levels; and • Be a leader in demonstrating how to bring new knowledge and tools regarding end-of-life to people in a way that will empower them to live more fully and to advocate for themselves and their loved ones. <p>These efforts will challenge traditional views about life and death and resolve fear so that people can benefit from the gift of mortality before they face it.”</p> <p><u>The Center’s focus</u> is to:</p> <ul style="list-style-type: none"> • Further the mission of quality of life at the end-of-life care for consumers in the State of Michigan; • Impact public policy making at the highest levels; • Challenge the organization’s internal and external end-of-life workforce with both intellectual and professional opportunities; • Provide Hospice of Michigan’s patients and families with evidence-based care; and • Drive process improvement initiatives to increase efficiency and effectiveness in delivery of care and service.

Maggie Allessee Center for Quality of Life (p. 2)	
Primary audience(s)	In the first phase the audience is internal; the Center will focus on the training and education of the Hospice of Michigan staff. In the second phase, the Center is greatly expanding its research and collaborative efforts.
Major activities	<ul style="list-style-type: none"> • Education • Research • Community outreach
Areas of emphasis	<ul style="list-style-type: none"> • Quality of care • Palliative care • Improving end of life care
Recent publications, activities	<p>The major activity in 2002 was opening the Center. Listed below are other 2002 Center activities, many of which were underway prior to the physical opening of the Center.</p> <ul style="list-style-type: none"> • Implemented distribution and public relations campaign for “A Caregiver’s Manual: Caring for a Loved One with Advanced Dementia,” an information manual for families in a collaboration with the Alzheimer’s Association of Greater Michigan. • Completed work on the University of Chicago/PEACE project (Palliative Excellence in Alzheimer’s Care Effort) • Completed University of Michigan Palliative Care Model. • Began project to assist a local hospital in establishing its own hospice services. • Began Telehospice project that allows Hospice of Michigan to offer Telehospice services as part of routine hospice care in Fremont, Michigan and urban Metro Detroit. • Improved education and training programs for staff, including Caring for Dementia patients training, and other topics. • Made presentations at various conferences about quality of life, end of life and palliative care. • Increased the use of metrics and quality indicators.
Board—size, membership, who appoints	The Center for Quality of Life is part of the Hospice of Michigan and as such does not have its own separate board of directors. However the new Center plans to put together an External Advisory Group. It will be used not for governance, but to provide advice on research and practices. Members will include physicians, economists, academics, researchers and representatives of other organizations.
Director’s background	<p><u>Dorothy E. Deremo</u>, who is President and CEO of both the Hospice of Michigan and the Center for Quality of Life, has a BA and MA in Nursing and an MA in Health Services Administration. She is a Clinical Nurse Specialist and Certified Adult Practitioner. Before joining Hospice of Michigan in 1998, Deremo served at various Michigan hospitals in a number of senior positions, including Associate Director of Nursing, Vice President of Patient Care Services, Vice President of Patient Care Services/Chief Nursing Officer, and Senior Nurse Executive.</p> <p><u>Gregory Grabowski</u>, who is responsible for day to day oversight of the Center, is Senior Vice President for Research and Development at the Hospice of Michigan.</p> <p style="text-align: right;"><i>continued</i></p>

Maggie Allessee Center for Quality of Life (p. 3)

<p>Director's back-ground (cont'd)</p>	<p>Previously he served as Corporate Development Director for Hospice of Michigan, and before that as Vice President Advancement/Alumni relations at a private high school. He has a BA in General Studies and is a Certified Hospice Administrator.</p>																														
<p>Staff size and titles</p>	<p>40.5 staff:</p> <ul style="list-style-type: none"> • Senior Vice President for Research and Development, Hospice of Michigan • Chief Medical Director • Director of Operations with following staff: <ul style="list-style-type: none"> - 11 Statewide grief support positions - 11 statewide volunteer services positions • Coordinator • Director of Programming and Education with following staff: <ul style="list-style-type: none"> - 6 Project Specialists (educators and research nurses) - 1-2 Researchers • Director of Organizational Quality with following staff: <ul style="list-style-type: none"> - 1 Clinical Corporate specialist, - 1 Quality and Corporate Specialist - 1 Quality Data Analyst - 1 Information Manager - ½ Medical Records Assistant <p><i>Note: Many of the line staff positions were transferred from other departments within Hospice of Michigan to the Center.</i></p>																														
<p>Annual budget and breakdown</p>	<p>\$3.24 million for 2003:*</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 80%;">Staff</td> <td align="right">\$2,073,000</td> </tr> <tr> <td>Benefits @25%</td> <td align="right">518,000</td> </tr> <tr> <td>Supplies, mail, services</td> <td align="right">32,000</td> </tr> <tr> <td>Printing</td> <td align="right">52,000</td> </tr> <tr> <td>Meals, miles, lodging</td> <td align="right">30,000</td> </tr> <tr> <td>Staff professional development</td> <td align="right">195,000</td> </tr> <tr> <td>Conference events</td> <td align="right">45,000</td> </tr> <tr> <td>Fundraising expense</td> <td align="right">268,500</td> </tr> <tr> <td>Equipment</td> <td align="right">5,000</td> </tr> <tr> <td>Public policy</td> <td align="right">5,000</td> </tr> <tr> <td>Cellular phone</td> <td align="right">4,000</td> </tr> <tr> <td>Contributions to other organizations</td> <td align="right">2,500</td> </tr> <tr> <td>Depreciation</td> <td align="right">4,000</td> </tr> <tr> <td>Miscellaneous</td> <td align="right">1,000</td> </tr> <tr> <td>TOTAL</td> <td align="right">\$3,235,000</td> </tr> </table> <p><i>* Note: 2003 will be the first full year in which the Center will have its own budget. Many of the operations and staff that now come under the Center were previously located in other departments of Hospice of Michigan. Examples of new positions under the Center include the Director of Operations and the Medical Director.</i></p>	Staff	\$2,073,000	Benefits @25%	518,000	Supplies, mail, services	32,000	Printing	52,000	Meals, miles, lodging	30,000	Staff professional development	195,000	Conference events	45,000	Fundraising expense	268,500	Equipment	5,000	Public policy	5,000	Cellular phone	4,000	Contributions to other organizations	2,500	Depreciation	4,000	Miscellaneous	1,000	TOTAL	\$3,235,000
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<p>Revenues</p>	<p>\$3.26 million projected for 2003:</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 80%;">Grants</td> <td align="right">\$ 393,000</td> </tr> <tr> <td>Direct mail</td> <td align="right">154,000</td> </tr> <tr> <td>Third party payer revenue</td> <td align="right">195,000</td> </tr> <tr> <td>Special events</td> <td align="right">93,000</td> </tr> <tr> <td>Bequests</td> <td align="right">200,000</td> </tr> <tr> <td>Subsidy from Hospice of Michigan*</td> <td align="right"><u>2,221,000</u></td> </tr> <tr> <td>TOTAL</td> <td align="right">\$3,256,000</td> </tr> </table>	Grants	\$ 393,000	Direct mail	154,000	Third party payer revenue	195,000	Special events	93,000	Bequests	200,000	Subsidy from Hospice of Michigan*	<u>2,221,000</u>	TOTAL	\$3,256,000																
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Maggie Allessee Center for Quality of Life (p. 4)	
Annual report	None to date.
Additional background information	Hospice of Michigan, of which the Center for Quality of Life is a part, was founded in 1994 with the merger of 10 hospices.
Sources of information for this chart	<ul style="list-style-type: none"> • Greg Grabowski, Senior Vice President for Research and Development, and Head of Community Relations, Hospice of Michigan • Bob Cayhill, Chief Financial Officer, Hospice of Michigan • Angela Harrison, Executive Secretary to the Chief Financial Officer, Hospice of Michigan • Barbara Pallazolo, Corporate Public Relations Director (phone interview (December 10, 2002) • "Maggie Allessee Center for Quality of Life FY 2002 4th Quarter Operating Plan" • Maggie Allessee Center for Quality of Life website: http://www.hom.org/mac.asp • Hospice of Michigan website: http://www.hom.org • "Hospice of Michigan Annual Report Highlights 2002" • "Hospice of Michigan Promotes Four in Quality of Life Center Positions," News Release, Hospice of Michigan, November 22,2002 • Hospice of Michigan department fact sheet for the Maggie Allessee Center for Quality of Life

MIDWEST BIOETHICS CENTER (MO)

Midwest Bioethics Center	
Address & Phone	<p>Midwest Bioethics Center 1021-1025 Jefferson Street Kansas City, MO 64105</p> <p>Tel. (800) 344-3829 or (816) 221-1100 E-mail: bioethic@midbio.org</p>
Website	<p>http://www.midbio.org</p>
Director	<p>Myra J. Christopher, President and CEO</p>
Type of entity	<p>Midwest Bioethics Center is a freestanding, practical bioethics center that was incorporated as a nonprofit organization in 1985. Its members include individuals and organizations. The Center is involved in a wide range of bioethical issues relating to end of life, research ethics, and health care disparity and diversity. This chart focuses on its work with respect to end-of-life and palliative care issues.</p> <p>The Center is also a Robert Wood Johnson Foundation National Program Office for Community-State Partnerships to Improve End-of-Life Care.</p>
Mission	<p><u>Mission:</u> To raise and respond to ethical issues in health and healthcare.</p> <p><u>Vision:</u> A society in which the dignity and health of all people is advanced through ethical discourse and action.</p> <p><u>Guiding Principles:</u></p> <ul style="list-style-type: none"> • To lead and promote the leadership of others • To think critically and listen actively • To address ethical issues unfettered by special interests • To collaborate with others who share our values • To work diligently toward our mission
Primary audience(s)	<ul style="list-style-type: none"> • Kansas City community – clinicians, policymakers and the public • Community coalitions in 15 Midwest states (including Colorado Regional) as part of the Last Acts technical assistance program • Trade and professional organizations (for example AARP, VA, etc.)
Major activities	<ul style="list-style-type: none"> • Education • Advocacy <p>Examples of major activities related to education and advocacy include:</p> <ul style="list-style-type: none"> – Raise and respond to ethical issues – Offer workshops and educational programs for professionals and lay people <p style="text-align: right;"><i>continued</i></p>

Midwest Bioethics Center (p. 2)	
Major activities (cont'd)	<ul style="list-style-type: none"> - Help providers throughout the country resolve ethical issues in clinical work - Help administrators and their staffs integrate ethics into their organizational structures.
Areas of emphasis	<ul style="list-style-type: none"> • Assist in development of such things as regulations, laws, curricula, and policy for institutions with respect to end-of-life issues. • Foster community and state partnerships to address end-of-life concerns. • Investigate ethical issues and practical solutions in end-of-life care for professionals, consumers, health care institutions and public policymakers.
Recent publications, activities	<p>Midwest Bioethics Center offers for sale numerous videos and publications — consortia documents, resource manuals, notebooks, articles, and its quarterly journal, <i>Bioethics Forum</i>, to enhance ethics education and promote discussion of ethics issues.</p> <p><u>Selected Consortia Documents and Resource Manuals:</u></p> <ul style="list-style-type: none"> • “Considerations Regarding Life-Prolonging Treatment Decisions for Residents of Long-Term Care Facilities” • “Considerations Regarding Withholding/Withdrawing Life-Sustaining Treatments” • “Honoring Do-Not-Resuscitate (DNR) Orders During Invasive Procedures” • “Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities” <p><u>Videos:</u></p> <ul style="list-style-type: none"> • “Nick and Sheila and the World: A Case Study about Patient Rights and Cultural Diversity” • “The Future of Dying” <p><u>Other Recent Activities:</u></p> <ul style="list-style-type: none"> • Developed a national network to promote collaboration among researchers and ongoing projects in establishing treatment guidelines for care of the terminally ill. • Assisted community groups in developing ethics centers in various Midwestern states. • Established a membership base of more than 1,000 individuals and 100 institutions. • Consulted with more than 100 healthcare-providing organizations. • Currently conducting a metropolitan-wide project called PATHWAYS to improve care of seriously-ill and dying patients in conjunction with a similar Robert Wood Johnson Foundation-funded initiative called Last Acts. <p style="text-align: center;"><i>continued</i></p>

Midwest Bioethics Center (p. 3)	
Recent publications, activities (cont'd)	<ul style="list-style-type: none"> • Held a day long meeting of concerned pediatricians, chaplains, social workers, community members and other pediatric health care providers in the Kansas City area to discuss care for suffering and seriously ill dying children. • Currently directs a national program funded by the Robert Wood Johnson Foundation called Community-State Partnerships. The purpose of this program is to help establish and support statewide partnerships to improve end-of-life care at the state level. Twenty-two statewide coalitions have carried out 2-3 year implementation projects. The program began in 1998 and will continue through mid-2003.
Board—size, membership, who appoints	21-member Board. Members of the Board are appointed by the Board. Significant efforts have been made to obtain representation from diverse groups including people with backgrounds in finance, clinical practice, philosophy and the law, and people from the community. Among others, the 2002 Board of Directors includes 2 people with MDs, 2 with JDs, 1 with an RN, 1 with a DMin, and 2 with PhDs.
Director's background	Myra Christopher became president of Midwest Bioethics Center in December 1994, and continues to serve as its executive director, a position she has held since the Center's inception in 1985 when she became its first employee. In addition to providing oversight to the Center, Christopher is national program officer of the Robert Wood Johnson Foundation's National Program Office for State-based Initiatives to Improve End-of-Life Care, which is located at Midwest Bioethics Center. She has a BA in Philosophy. Her prior experience in community involvement in schools, churches, etc.
Staff size and titles	13 professional staff plus administrative support. Professional staff include: <ul style="list-style-type: none"> • President and CEO of the Midwest Bioethics Center • 1 Vice President of Programs, Research and Communication • 1 Vice President of Strategic Initiatives and Administration • 9 Program Associates including Editor • 1 Director of Communications. • Administrative support
Annual budget and breakdown	\$1.6 million total budgeted for 2003. Half of budget is for staff.
Main funding sources	<ul style="list-style-type: none"> • Substantial donor gifts • Grants • Membership base contributions • Earned income (consultations, videos, etc.)
Annual report	None.

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Additional background information	<ul style="list-style-type: none"> • Christopher has personally engaged with people on end-of-life and palliative care efforts in Colorado. While similar efforts have been successful in other states, Christopher reports they did not succeed in getting the players to come to terms in Colorado. • Paradigmatic “grass roots” founding of the center.
Sources of information for this form	<ul style="list-style-type: none"> • Myra Christopher, President and CEO • Web site • “National Alliance of State Initiatives” • “Lightening Rods of Reform, 2002 Annual Meeting of Community State Partnerships to Improve End-of-Life Care”