Center to Advance Palliative Care
National Hospice and Palliative Care Organization
NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

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Photos by D. Brent Miller

Copies of this manual may be ordered through the **NRHA** (*www.nrharural.org*) **Item No. PU0705-71;** or the **NHPCO Marketplace** (800/646-6460 *www.nhpco.org/marketplace*). **Manual + CD: Item No. #820774**; or **CD Only: Item No. #882078.**

This publication was funded by the Health Resources and Services Administration, Office of Rural Health Policy through a cooperative agreement.

WELCOME

Providing Hospice and Palliative Care in Rural and Frontier Areas is a technical assistance toolkit designed to support providers seeking to enhance access to such services. This document also celebrates the wonderful work already in progress in rural and frontier communities from coast to coast and portrays examples of innovative practice and high-quality hospice and palliative care. We wish to convey our special thanks to the providers who contributed their time, policies and procedures to this effort.

We know that 39 percent of America's hospices define themselves as rural and 40 percent serve both urban and rural areas. The number of palliative care programs serving rural areas is also growing. However, we have yet to reach the goal of hospice and/or palliative care access for all rural and frontier areas. It is our hope that the toolkit will assist in achieving this outcome.

The National Rural Health Association, the National Hospice and Palliative Care Organization and the Center to Advance Palliative Care will continue to assist with the development of access to high quality hospice and palliative care services in general and for rural and frontier communities in particular. Our respect and admiration go out to each of you who deliver these services every day.

We encourage and welcome your comments on this product.

J. Donald Schumacher, Psy.D, *National Hospice and Palliative Care Organization*

Diane E. Meier, M.D., *Center to Advance Palliative Care*

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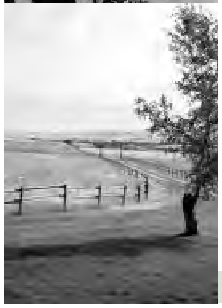

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Chapter 1:

Introduction

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The National Rural Health Association (NRHA) of Kansas City, MO, a nonprofit association of individual and organizational members who share a common interest in rural health, is dedicated to the mission of improving the health of rural Americans and providing leadership on rural health issues through advocacy, communications, education and research.[1] NRHA believes that all Americans are entitled to an equitable level of health and well-being established through health care services regardless of where they live.

An important but often overlooked aspect of health and well-being is assurance of appropriate care and support when people are experiencing chronic, progressive illness or are approaching the end of their lives. In 2004, NRHA received a grant from HRSA's Office of Rural Health Policy to support development of a comprehensive manual on providing hospice and palliative care in rural and frontier areas.

NRHA in turn subcontracted with the National Hospice and Palliative Care Organization (NHPCO) of Alexandria, VA, the professional membership organization representing America's hospice and palliative care providers, and its collaborating partner the Center to Advance Palliative Care (CAPC), a Robert Wood Johnson Foundation-funded national initiative based at Mount Sinai School of Medicine in New York City, dedicated to increasing the availability of quality palliative care services in hospitals and other settings. The subcontractors agreed to produce this manual as a resource for communities, service providers and policy-makers, offering tools, suggestions and examples of successful strategies for extending the palliative care continuum across rural America.

The manual is designed to encourage the development, enhancement and wider dissemination of hospice and palliative care for residents of America's rural and frontier communities by encouraging existing care providers to continue promoting access to care, informing other health care providers serving rural communities of the opportunities for collaboration in palliative care development, and inspiring leaders of communities that now lack hospice and palliative care to organize and develop services responsive to the specific needs of their communities. In so doing, access to these services can be increased, helping to ensure that all Americans, regardless of where they live, can enjoy the benefits of quality hospice and palliative care at the time when they need it most.

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[1] From National Rural Health AssociationWebsite: www.nrharural.org.

The manual compiles results from a dozen site visits to rural end-of-life care providers during the summer and fall of 2004, 20 responses to an extensive written questionnaire, four additional telephone interviews with providers, dialogue on the NHPCO rural listserv, and input and review by NRHA's Palliative Care Advisory Committee. It identifies general areas of best practice and illustrates them with brief anecdotes as well as vignettes drawn from the site visits. These collective practices are not offered prescriptively as the right or only way to proceed with hospice and palliative care development in rural settings but as illustrations of real-world solutions to specific circumstances.

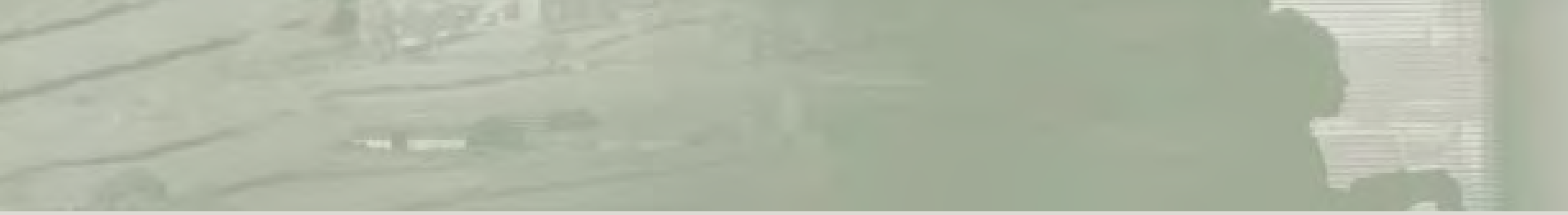
The remarkable track record of accomplishments and innovative responses by rural hospices and palliative care providers such as those profiled in this manual clearly reflects the strengths of America's rural providers. The often-cited character and personality traits of rural communities — independence, self-reliance, willingness to help a neighbor in need — enable and inspire the hospices and palliative care providers that serve those communities. These successful rural hospices and palliative care programs have developed multilaterally, collaborating and partnering with a broad range of other agencies and services in their communities. These programs reflect the character of the communities they serve; in turn, the providers are viewed as valued community assets.

What Is Rural Hospice and Palliative Care?

One of the first questions in writing a manual on rural/frontier hospice and palliative care is to ask what *rural* means in this context. What is a rural hospice or palliative care provider? Are these providers of care markedly different than their non-rural counterparts? Do rural providers face distinct challenges and do they enjoy compensating advantages?

A detailed exploration of rural communities, their challenges in providing hospice and palliative care services, and models of rural providers comprises much of Chapter 2. But there is an underlying dilemma behind these definitional questions that we believe needs to be openly acknowledged. For some of America's smallest or most geographically isolated hospices, there is occasional skepticism about non-rural hospices — their motivations, their potential to become competitive threats, even the relevance of their experience and lessons learned.

What can a hospice with a census of 10 patients or less learn from one with a census of 100 — or more? What can a hospice with a census of 100 learn from one with a census of 10 or less? Site visit findings demonstrate that every hospice and palliative care provider can teach and learn from others.



Our goal in compiling this manual is to ground it in real-world experience — to describe actual challenges and to compile real solutions from hospices and palliative care organizations serving rural and frontier areas. To achieve this outcome, we visited selected sites in order to report first-hand how rural hospices and palliative care organizations operate, confront and overcome actual challenges, and build on the strengths of their communities. Site visits are a particularly important reference point for this work given that a review of a bibliography of nearly 2,000 medical journal articles on palliative care identified almost no relevant, published information on the differences and particular challenges and opportunities of hospice and palliative care in rural settings.[2]

There were many more noteworthy sites recommended to us than we could visit in person, given resource constraints as well as limitations on the potential sites in terms of their ability to accommodate site visitors within the project's time frame. The dozen rural sites we visited offered rich clinical and administrative practices reflecting varied models and settings, including palliative care and/or Medicare-certified and non-certified hospices and free-standing/community-based, hub/regional, hospital-based and home health agency-based models.

These sites were chosen not as the "best" or "most representative" of rural providers but because they present interesting features, diverse circumstances, innovative programming and rural settings for care in all regions of the country, and because they were available and accessible within the project's time frame. In several cases sites in reasonably close proximity were bundled together to maximize our efficiency and thereby the breadth of experience we could incorporate within the project.

One thing these different settings have in common: they are all happy to share their success stories about how they have established mutually supportive community relationships and how they have crafted the basic tasks of operating a hospice or palliative care service. Some of the sites are profiled through narrative vignettes; all contributed valuable insights, many of which are referenced in the text. For those we could not visit in person, extensive questionnaires and/or telephone interviews provided additional information and innovations.

Admittedly, our database includes a relatively small sample of non-hospice palliative care programs of distinctive rural character and setting, so we had fewer opportunities to portray the emergence of this newer category of care in a rural context. We have, however, tried to reflect the issues of non-hospice palliative care at every opportunity throughout this manual.

We are particularly pleased to include a vignette from one hospice with a census of approximately 10 patients a day. We recognize the extraordinary circumstances encountered by those who manage to serve patients and families despite resources limited by size and we hope our characterization captures their issues at some level.

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[2] *Clinical Practice Guidelines for Quality Palliative Care, Bibliography.* National Consensus Project for Quality Palliative Care: *www.nationalconsensusproject.org.*

Chapter 1: Introduction

Every rural provider is unique, as the sites we visited so amply demonstrated. And yet all hospices and palliative care organizations share the goal of caring for patients and their families at a time of life-threatening illness.[3] For providers, whether rural or not, their work demands answers to the questions of how to provide access, ensure quality of care and achieve financial stability.

Defining Hospice and Palliative Care

Hospice and palliative care are the recognized models for quality compassionate care for people facing a life-threatening or life-limiting illness. According to the National Consensus Project for Quality Palliative Care:[4]

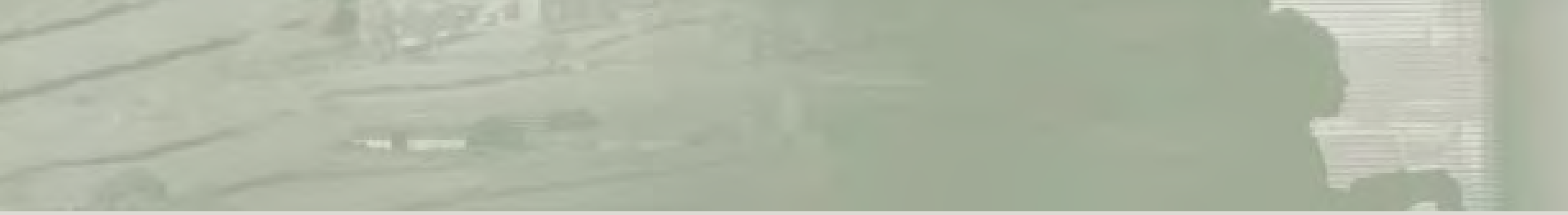
> The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivery of care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

Hospice is a specially designed program of palliative care for patients whose disease prognosis is determined to be terminal. Hospice programs offer an inclusive care management approach focusing on pain management, symptom control and comfort care.

Like hospice care, palliative care can be provided wherever the patient and family choose to receive it, including the patient's home, hospital, nursing home or assisted living facility. Palliative care extends the principles of hospice care to a broader population of patients who could benefit from receiving this type of care earlier in their illness or disease process. Palliative care, which can benefit patients from the point of diagnosis of a serious illness, ideally would segue into hospice care as the illness progresses.[5]

[3, 5] *"What Is Hospice and Palliative Care?"* National Hospice and Palliative Care Organization, Alexandria, VA: www.nhpco.org.

[4] *Clinical Practice Guidelines for Quality Palliative Care*. National Consensus Project for Quality Palliative Care: www.nationalcensusproject.org



For people living in sparsely settled, isolated rural communities, these concerns are cast in sharp relief. Rural families are used to counting on their neighbors in times of crisis, because they must. Contemporary medical care, even when focused on palliation rather than cure and even when provided in the home, can be complex and technologically challenging, alienating the care recipient and care providers. Whereas in the past, care was often provided by families living in multi-generational households, with many hands to share its demands, the current reality is different. Adult children may live significant distances from aging parents, having left their rural communities to pursue employment opportunities.

Most rural residents, like most other Americans, would prefer to be in their own homes and familiar milieus when facing a life-limiting illness — if this can be done safely, securely, comfortably and without undue burden on their families. Often this preference is realized with the organized support of a hospice or palliative care program. When a rural resident is admitted to a residential or long-term care facility, which may be some distance from the home, hospice and palliative care services can offer continuity and serve as an important linkage to known providers.

America's providers of hospice and palliative care believe that all Americans should have access to this kind of care, regardless of where they live, and that this care should be delivered in their homes (including a long-term care facility if that is now their home), if that is possible and the patient's preference. This commitment is realized by the existence of hospice and palliative care providers in communities large and small, from coast to coast.

Rural communities and landscapes have presented providers with some distinct barriers and challenges, which will be described throughout this manual. The experience of sites surveyed for this project also demonstrates the great diversity of rural communities — diversity of economic bases, socio-economic status, access to social capital and other resources, local cultural norms and expectations, and increasing cultural diversity. Rural hospices and palliative care programs have addressed the full range of America's landscape features in caring for patients who live on mountains, islands, swamps, deserts and, in rural Alaska, in places that are accessible only by airplane.

The Continuum of Palliative Care

Hospice: Comprehensive services are provided by an interdisciplinary team wherever the patient is, and include physicians, nurses, social workers, chaplains, counselors, certified nursing assistants and volunteers. Care focuses on meeting the needs of patients and their loved ones, and a care plan is designed specifically for each patient. Ninety-seven percent of hospices in America are Medicare-certified,[6] and receive third-party reimbursement from Medicare, Medicaid and most private insurance plans. The specific services required from hospices participating in the Medicare program are described in *Appendix C*. Some hospices have continued to function as volunteer hospices while not seeking insurance reimbursement *(see also p. 25)*. While the Medicare hospice benefit is the primary funding source for hospice care in America, many certified hospices emphasize that their philosophy and scope of care are broad and inclusive, recognizing that Medicare regulations and limitations apply specifically to the services rendered within that context.

Palliative Care: Palliative care services are offered by health providers such as hospices, hospitals, home health agencies or nursing facilities — often through collaboration by two or more such entities. Licensed physicians and advanced practice nurses can bill Medicare, Medicaid and many other third-party payers for relevant professional services. The two most common approaches to inpatient palliative care are a multidisciplinary consultation service that responds to requests by attending physicians or other health professionals and/or a palliative care unit with a dedicated staff rendering specialized services, often in space thoughtfully designed to promote privacy and comfort. Increasingly, palliative care is offered in community-based and outpatient settings, as well.

Inpatient Options: While the majority of hospice care is provided wherever the patient calls home, partnering relationships with nursing homes, scatter beds or contract inpatient units in hospitals, freestanding hospice inpatient facilities and residential care options are also part of the continuum of care for acute symptom management or family breakdown. These settings provide a place for those who are not able to remain at home during their final days.

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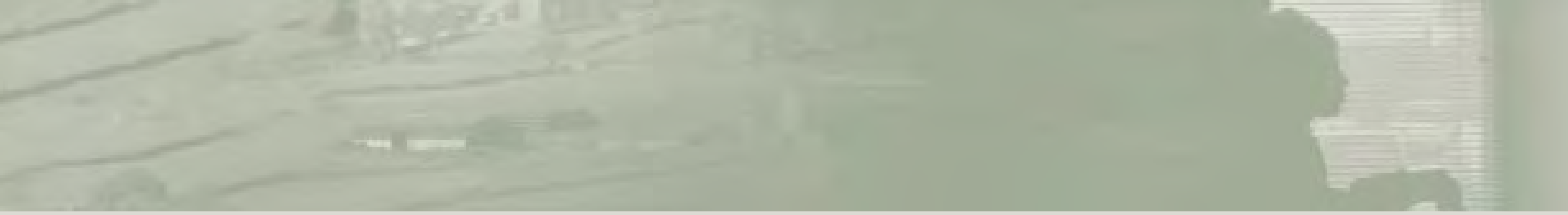
[6] *2003 NHPCO National Data Set Summary Report – Demographics and Operations, National Trend Summary – 2000-2003.* National Hospice and Palliative Care Organization, Alexandria, VA.



Bereavement: Another important component of end-of-life care is grief support for the bereaved survivors of hospice patients and/or others in the community who have suffered a loss. Bereavement support is provided in a variety of contexts, including support groups, individual counseling, telephone follow-up, informative mailings, crisis response, school and workplace outreach, and specialized services such as grief camps for children.

Special Needs: Specialized services rounding out the care continuum include pediatric hospice and palliative care services for children living with life-threatening illnesses, programs with a special disease focus such as Alzheimer's, HIV/AIDS or end-stage renal disease, and a variety of creative collaborations with other health care providers. Hospice and palliative care professionals benefit from partnering with community agencies and other providers, broadly defined, to develop inclusive responses to unmet needs.

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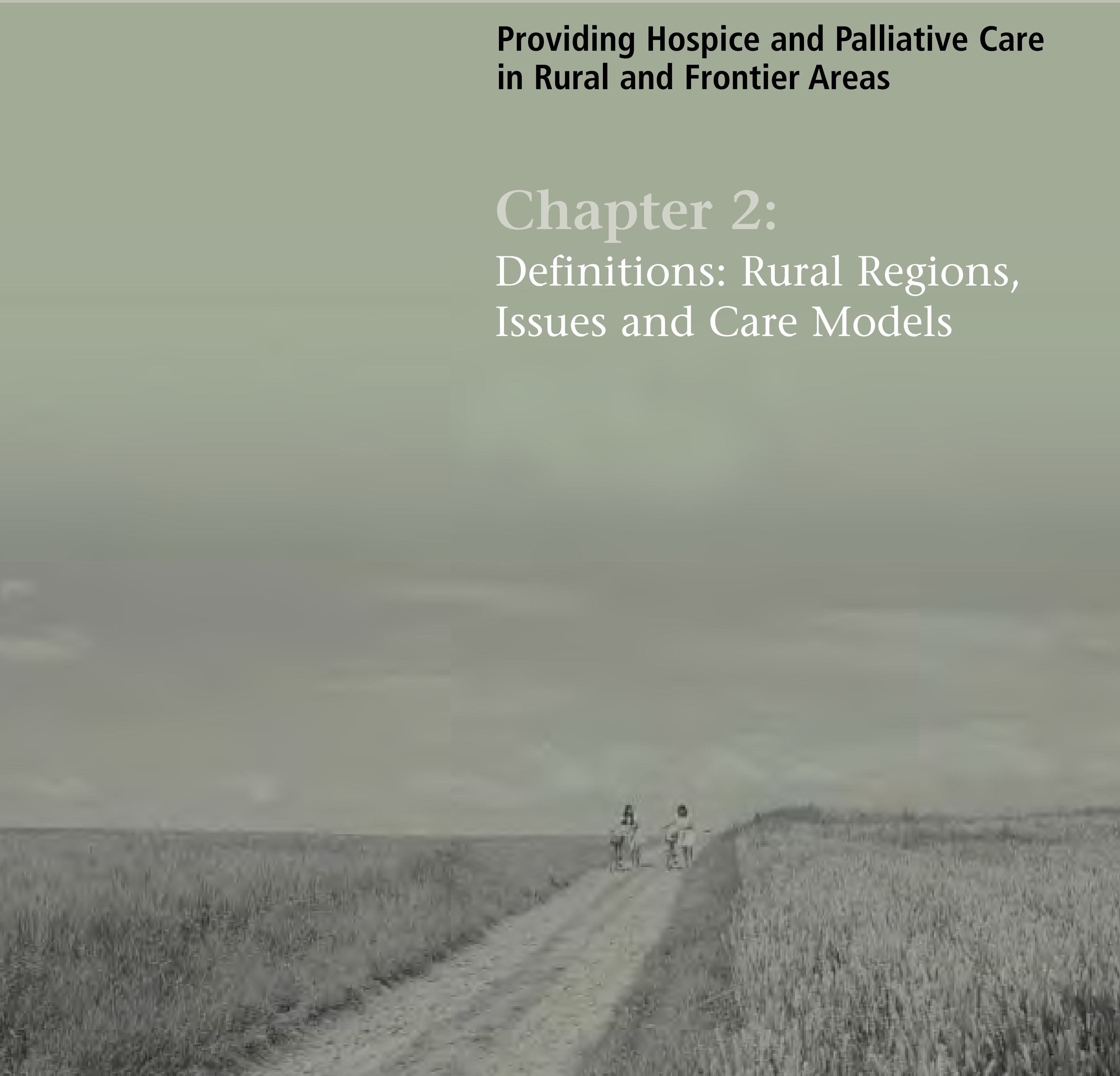
Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 2:

Definitions: Rural Regions, Issues and Care Models



Chapter 2: Definitions: Rural Regions, Issues and Care Models

An early challenge for this project was to first define "rural" and then place the varieties and models of care providers within that rural context. Based on our findings, however, we have made a conscious decision to avoid narrow descriptions and to simply recognize that rural/frontier regional and local circumstances and providers vary.

The Federal government has defined rural as those areas not designated as parts of metropolitan areas by the Office of Management and Budget. There are, however, some very large counties in the United States, particularly some in the West, that have large cities but also major parts of the county that are very rural in character. To compensate for the inherent weakness in using whole counties as the basis for defining rurality, ORHP commissioned Dr. Harold Goldsmith, a demographer, to develop a method of identifying rural areas inside Metropolitan counties. The "Goldsmith Modification" used Census data on commuting to identify census tracts inside large, Metropolitan counties that were isolated and not densely populated. Since the original Goldsmith Modification was based on 1980 Census data, ORHP has participated in the development of a more current approach to designating rural areas inside metropolitan counties. The Rural Urban Commuting Areas (RUCAs), developed at the University of Washington's WWAMI Rural Health Research Center, use Census commuting data to define a continuum from densely populated urban areas, to very isolated rural areas.

The concept of what is meant by "Frontier" has been even less sharply defined than "rural." Frontier is understood to represent both extremely low population density and isolation. One standard defined Frontier counties based on a density of fewer than 6 people per square mile. An alternative definition has been developed by the Frontier Education Center of Albuquerque, NM:

In 1997 the Frontier Education Center convened a group of frontier providers and policy experts to develop a consensus definition of “frontier.” Early on, it became clear that defining frontier solely by population was not an adequate approach. For example, in some large counties, the presence of a city in one corner skews population density and overshadows the existence of many large frontier areas. At the same time, small counties that are clustered close together may have low population densities, but exist within very metropolitan areas. Furthermore, a key component to frontier life is distance. Areas with population density as high as 20 people per square mile[7] could be considered frontier if the community were located at a great distance or travel time from the closest significant service center or market. The Frontier Education Center adopted a consensus definition of frontier which is based on a matrix that includes population density and distance in miles and travel time in minutes from a market-service area.

Currently, the Office for the Advancement of Telehealth (OAT) in HRSA has been charged with developing a Frontier definition using “population density, travel distance in miles to the nearest medical facility, travel time in minutes to the nearest medical facility and other such factors.

This consensus definition has been formally adopted by both the National Rural Health Association and the Western Governors Association.[8] Based on figures from the 2000 U.S. Census, about nine million people live in the 812 counties that meet the standard for frontier (out of a total of 3,190 U.S. counties) located in 38 states. Although frontier areas constitute only about 3 percent of the U.S. population, they comprise about 56 percent of the country’s land area. A related term is *wilderness*, which could be understood as even more isolated and low density than frontier. It is also worth emphasizing that all but a few of the hospice and palliative care programs studied for this report are located in incorporated towns of varying sizes, even if they are surrounded by vast expanses of low population density.

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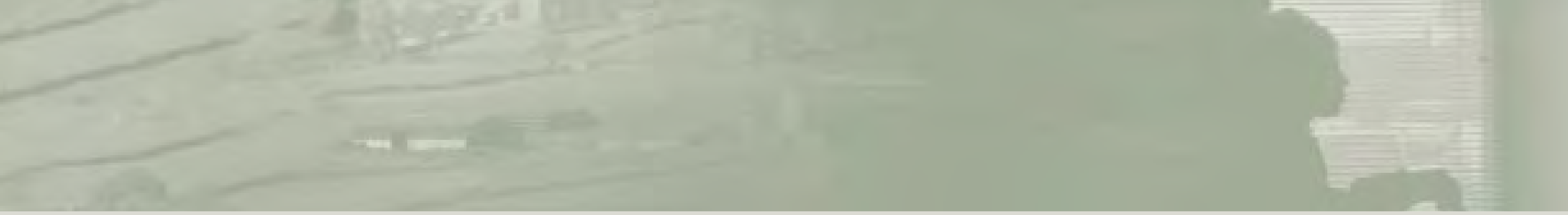
[7] The Frontier Education Center reports that the national average for population density is almost 80 people per square mile. For more information, or a complete list of frontier counties, *see Appendix D* or www.frontierus.org.

[8] 2000 Update: Frontier Counties in the United States.” Frontier Education Center, Albuquerque, NM.



Providing Rural/Frontier Hospice and Palliative Care

For many care providers, rural is partly a matter of self-perception. The designation as rural or frontier also implies a set of issues in delivering care in isolated areas. Those issues include patient inaccessibility and long driving times required for home visits or for transporting a patient to a health care facility; incomplete access to professional personnel, philanthropic resources, medical supplies, cell phone service and/or paved roads; and a patient census that sometimes renders economies of scale and efficiencies of operation difficult to achieve.

Geographical barriers, including mountains, rivers, islands, snowfall and floods (discussed at greater length in Chapter 11), may define the rural character of an agency more completely than sheer distances or population density. Widely-reported anecdotal evidence suggests that in areas of low population density, the per-unit cost of providing care is likely to be higher than national averages because of factors such as those mentioned above. Paradoxically, regionally adjusted reimbursement rates set by Medicare for rural settings are most likely *lower* than the national averages.

Providing comprehensive, high-quality hospice and palliative care under such circumstances stretches providers and challenges their ingenuity and creativity to offer ready access to high-quality services. However, our findings demonstrate that many providers in rural or frontier settings are doing a remarkable job of meeting their communities' care needs.

Rural/frontier providers have identified the following additional challenges in meeting their service goals:

- Assuring access to hospice- and palliative care-trained physicians;
- Assuring access to qualified social workers;
- Creating access to specialized medical expertise and consultation, including such specialties as oncology, neurology or hematology and the medical specialty of palliative care;
- Contracting with Critical Access Hospitals and Rural Health Clinics (see *Appendix B*);
- Dealing with real or perceived competition between providers of hospice and palliative care; and
- Overcoming limited information systems and communications access resources.

Demographics of Rural/Frontier Areas

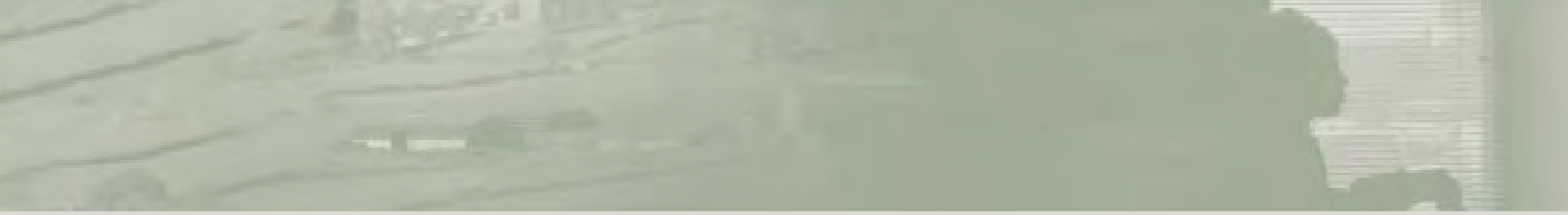
While the economies of some rural communities have limited employment and/or wage and salary opportunities, several of the sites visited are populated by professionals who have made a choice to live in the area based on perceived quality of life. Many rural and frontier areas reflect an aging population, although older citizens often constitute a rich source of professional experience, board service and/or program volunteers. It is also true that former images of America's rural communities as ethnically homogenous no longer hold true in many locales as changing demographics and an influx of new residents redefine the cultural mix.

According to demographic hospice industry data for 2003 gathered by NHPCO, 21 percent of hospices describe themselves as urban, 39 percent as rural and 40 percent as both urban and rural. Clearly, providers based in or serving rural areas constitute the majority of the 3,200 operational U.S. hospices. There is not yet a comparable database for non-hospice palliative care providers, although there is significant growth in this sector in both urban and rural areas.

Varieties of Rural Hospice/Palliative Care

Rural providers come in as many different organizational models as do their non-rural counterparts — including community-based, hospital-based, home health agency-based and county health department-sponsored. The tax status of rural providers may be not-for-profit or for-profit — another characteristic shared with urban counterparts. New varieties of non-hospice palliative care are also emerging in many rural communities.

The most familiar rural hospice model is the independent, community-based non-profit, typically organized by a volunteer group of community leaders and health professionals in response to a recognized need. Such hospices often serve a single community and surrounding countryside, a single county, or several adjacent rural counties. In trying to gain a clearer understanding of the constituency of rural providers, several other terms arise that are worth exploring.



Volunteer Hospice: From the early days of hospice care in America, a volunteer-intensive hospice has been generally understood as an agency that preserved its roots through the use of professional team members (especially nurses) volunteering their time to provide direct patient care, along with the more conventional use of lay volunteers to provide supportive services to patients and families ***(see also Chapter 9).***

The more volunteers a hospice uses in professional and non-professional roles, the more strategic it can be with its few paid staff positions. Before there was Medicare reimbursement in 1983 or insurance reimbursement from private carriers, most hospices used this model to deliver services. Many small hospices have used volunteers in a variety of roles ranging from professional services such as medical back-up to meeting the personal needs of patients and families or paid providers, including running errands and/or providing transportation.

This understanding of what constitutes a volunteer hospice has been joined by a second meaning, related but distinct, created by hospice licensure laws in a number of states. In those states, a new category of licensure for *volunteer hospices* permits agencies to provide patient care volunteers, fund-raising support, bereavement and other non-compensated aspects of hospice care, often under a partnering contract with a Medicare-certified hospice. As required by the Federal Centers for Medicare and Medicaid Services, the latter retains professional management responsibility for the patients it enrolls, but the two contracting organizations collaborate in obtaining and providing the resources necessary to deliver hospice care. In some cases the volunteer hospice is an important bridge between the rural community and the Medicare-certified hospice.

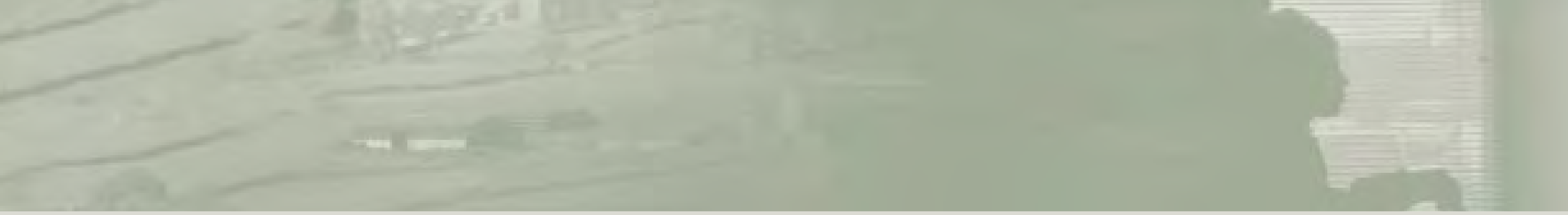
Hospice Alliances, Partnerships and Confederations: Rural hospices in some regions have found various means of working together with their hospice neighbors in order to leverage their respective strengths and locations in rural service delivery. Formal merger or acquisition to create a single corporate entity is one possible outcome. Other approaches include the formation of purchasing groups, alliances to represent members in negotiations with third-party payers, and confederations of hospices in a state or region that have banded together for purposes of mutual support and the sharing of information.

A collaborative of providers can develop mutually beneficial projects, such as sharing the salary of a medical director, the costs of a joint inpatient unit or residence, the resources needed for professional education and volunteer recruitment and training. Given developing telecommunications technology, some rural sites are also in a position to develop productive partnerships with an academic medical center, a large urban hospice or another health care provider for access to education, library resources and/or professional consultation.

Hub Hospice: In this model of hospice care, a central office supports one or more satellite offices in surrounding rural areas, typically with administrative back-up from the hub to the satellite, centralized business functions and greater or lesser degrees of decentralized staffing and designated services housed in the satellite offices. Sometimes the hub hospice opens satellite offices on its own initiative in underserved areas or follows the pattern of its parent health system's satellite outposts. In other cases, community groups request the larger hospice to come into their communities or to assume the management of a struggling rural hospice provider. Different forms of affiliation can balance centralized control with decentralized community ownership.

Regional Hospice: If enough satellite offices extend across a broad geographical expanse a hundred miles or more from the hub, this combined organization may be better described as a *regional hospice program*. Examples from our research demonstrate that some of the most rural areas are served by urban-based organizations, which in turn rank among the largest and most prominent end-of-life organizations in the country.

When a large, urban-based or hub hospice serves a rural community, it assumes the responsibility for tailoring its services to meet the needs of a different constituency. These regional hospices may enjoy the benefits of economies of scale and shared administrative resources. However, the regional hospice must also address most of the fundamental challenges of serving a rural community — low population density, longer driving times and geographic barriers; establishing credibility; and building relations with a network of other providers, local physicians and leading members of the community. The success of the outreach depends on the presence of a hospice and/or palliative care champion or staff representative residing in the community. This hometown visibility/credibility must be addressed regardless of the hospice's model or base.



Opportunities for Growth

The opportunities for NHPCO and CAPC, working with NRHA and with professional associations of hospice and palliative care physicians, nurses and others, state associations and other key constituencies, is to provide meaningful support for providers operating in rural and frontier communities. A potential list of such supportive offerings might include telephonic consultation on pain and symptom management issues, hosted listservs, traveling educational programs and targeted advocacy with insurers to obtain appropriate benefit coverage.

It is also important to recognize and nurture the accomplishments of hospice and palliative care providers in rural areas. These providers have a remarkable track record of success. Their effective integration within the communities they serve in turn creates resources unique to these settings. There is great diversity in communities that share similar population density. We have discovered that there is much to be learned by better understanding how local demographics, geography, economies and "social capital" combine to build a template that on the one hand is unique but may also lend itself to partial replication and adaptation in other settings.

Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 3:

Needs Assessment and Data Gathering

Chapter 3: Needs Assessment and Data Gathering

How does the provider know that hospice and palliative care services are fulfilling a need? How are additional unmet needs identified? Do satisfaction surveys filled with praise from families and loved ones provide sufficient evidence to demonstrate that community care requirements are being met?

Needs assessments can be valuable tools in defining community palliative and end-of-life care services requirements, as aids in strategic planning, and as a data resource for targeting new program development. To better serve communities, it is vital to both assess needs and continually evaluate program effectiveness and relevance in a changing environment.

This section of the manual illustrates the importance of conducting needs assessments and provides examples of both formal and informal approaches to defining need employed by hospices and palliative care providers. Although formal methodologies are likely to produce a higher level of validity and confidence in the results, informal, ad-hoc approaches also have merit. How to balance concerns of comprehensiveness and reliability of results with limited time and other resources is a dilemma that must be resolved by each provider.

While providers are responsible for assessing community care needs, state Certificate of Need (CON) laws have been established in some states in order to contain costs and control market expansion. These CON requirements govern the establishment of new health care services, especially beds in acute care and long-term care settings. In 12 states,[10] CON laws define the requirements that must be met to justify the establishment of a new hospice or the expansion of an existing hospice to a new area.

Each state’s methodology for determining need is a bit different. For one state it could be the number of patients admitted in a county compared to the mortality statistics for that county. In another, the requirement defines unmet need for hospice services based on the number of patients who died from “hospice-eligible causes” (usually excluding homicide and accidents). In some states, there are specific CON requirements pertaining to hospice-owned and/or operated inpatient or residential facilities.

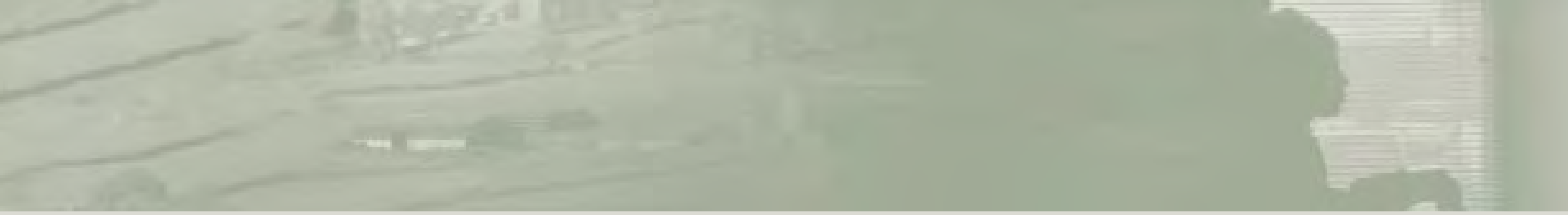
[10] The 12 states with hospice certificate-of-need laws are Arkansas, Florida, Hawaii, Kentucky, Maryland, New York, North Carolina, Rhode Island, Tennessee, Vermont, Washington and West Virginia.

Defining and Assessing Need

Although there are many ways to conduct a needs assessment, the process should include recruiting a group of community members to participate in the definition of purpose and focus, identifying relevant demographic and health services availability and utilization data, and creating an assessment of the results. What will help describe a community's hospice and palliative care needs? The information will consist of data from a variety of sources. Data may include the following:

- Demographics of the community — for example, average age and the distribution of the target population by various categories including ethnicity;
- Disease statistics, usually obtained from the county health department or state vital statistics division;
- List of health care organizations/agencies that provide related services;
- A definition of unmet or under-met service needs;
- Identification of the unique characteristics that differentiate palliative care and/or hospice services from other services in the community;
- Vital statistics, including cause of death, age at death and location of death;
- Loss data;
- Community residents' satisfaction with current hospice and/or palliative care services, obtained through interviews; and
- Community members' preferences about hospice and palliative care.

Individuals interviewed during site visits underscore the importance of including a broad base of community representatives in defining and implementing the needs assessment process. Ellie Ward of Dare Home Health and Hospice in Manteo, NC, states that it was beneficial to her agency's needs assessment process to "allow community members and key community representatives to define need."



Examples of individuals who could be recruited to participate in the needs assessment process include:

- Community residents;
- Representatives from other community organizations including the hospital and long-term care facilities;
- Representatives from other community service providers such as a librarian, store owner, chiropractor or dentist;
- The president of a fraternal organization, the Rotary Club, another service club or the Chamber of Commerce;
- Pastors or leaders of local faith communities;
- Someone involved with the local food pantry or other emergency relief organization;
- An influential local business person such as the feed store owner;
- A county extension staff person active in community events and volunteer work;
- Someone who organizes the town’s annual parade, festival or other special events;
- Someone who works on civic clean-up and beautification;
- Representatives from other small organizations and entities in each of the counties the provider serves.

Thinking expansively, other informants could be drawn from groups such as pediatric providers, health care professionals caring for patients with non-cancer diagnoses, and staff from senior centers, employee assistance programs, school and workplace grief programs, sudden death and trauma organizations, and veterans’ groups.

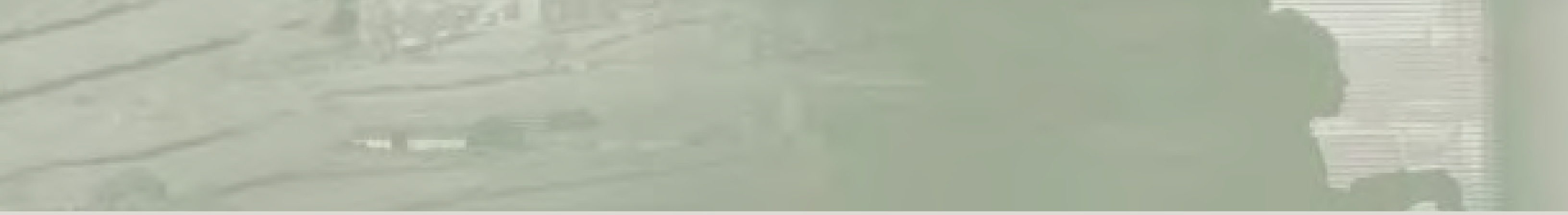
The questions to be answered by the needs assessment process include: Are initial assumptions substantiated by the findings? Are proposed services responsive to identified needs? Related topics of organizational quality assessment and improvement are discussed in Chapter 12.

Examples of Rural Needs Assessments

Hospice of the Wood River Valley in Ketchum, ID, conducts an ongoing, annual needs assessment process through one-on-one interviews. Key informants in the community are identified by the hospice's Board of Directors and include physicians, major donors and community leaders. One of the key questions asked is: "What would constitute success for hospice?" Answers to the first round of these interviews helped to shape the agency's planning, and these informants were revisited the following year for their perspectives on progress to date.

Rounds of needs assessment interviews continue to be administered almost every year, using a brief, five-item questionnaire called the "Planning and Goal Setting Interview" ***(see attachment on p. 143)*** and targeting different community groups each year. The hospice's Executive Director, Carolyn Nystrom states, "One year we gave five forms to each board member and told them they could talk to anybody they wanted to." The Coroner for Blaine County, a former member of the Hospice Board of Directors, has also been helpful in gathering and analyzing statistics on all deaths in the county, which enables comparisons between those findings and the number of patients served by the hospice.

The experience of living and working in a rural community also provides informal opportunities to discuss local preferences. Sandy Kuhlman, Director of Hospice Services, Inc., in Phillipsburg, KS, states that the "sense of community" provides many opportunities for conversations regarding needs.



Additional Sources of Information

Specific examples from hospices and palliative care programs provide helpful ideas for gathering the information cited above:

- Current surveys and other quality measures used by hospice, palliative care and other community programs. Teri Rostberg, Director of Hope Hospice and Palliative Care, Inc. in Rib Lake, WI, states that the hospice's informal needs assessment includes calculating the number of referrals and admissions and then comparing it to the number of deaths. Also examined are the reasons why some referrals did not turn into admissions;
- Jon Franstvog, Director of St. Benedict's Health Care Center in Dickinson, ND, a long-term care facility with a unique organizational approach to providing end-of-life care for the majority of its residents, describes its informal needs assessment as examining the death and discharge summaries completed by families six to eight weeks after the loss of a loved one. Information is gathered on positive outcomes and areas for improvement;
- The Delta County site of Hospice and Palliative Care of Western Colorado, Grand Junction, CO created the Spiritual Advisory Council to identify special population needs. The Chamber of Commerce provides descriptive information on specific faith-based populations. Those identified as underserved by the hospice can be contacted to determine how the provider might better response to their specific concerns and preferences;
- Hospice of the Red River Valley in Fargo, ND, did not conduct a formal needs assessment for its expansion to new offices, although it carefully tracks patient census data by office. The hospice's administrators view growth in patient census as evidence of programmatic success in identifying and filling community needs.; and
- Hospice of North Iowa in Mason City, IA also uses census information to project future census and thereby to project the need for hospice and palliative care services in its community.

Examining family satisfaction surveys, as well as collecting morbidity and mortality statistics, helps to illustrate some of the needs of a community. However, providers learn about unique current care needs by engaging their communities in the assessment process. ***(See attachments on pp. 141-169.)***

Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 4:

Creating Capacity

Chapter 4: Creating Capacity

Creating capacity means extending the community's vision of excellent hospice and palliative care through the expansion and broader utilization of these services. In rural and frontier settings, creating capacity depends on mobilizing a broad range of partners and constituencies to participate in reaching that vision. Creating access to readily available, high-quality services and thereby winning community respect as the leader and expert on hospice and palliative care is a fundamental element of organizational success and a mandate shared by providers in both rural and urban markets.

Open Access to Services

Capacity can also be defined in terms of improved access to hospice and palliative care. Access may be extended by inclusive and flexible service definitions and by strategies to overcome external and internal barriers. In considering what *open access* might mean for the rural and frontier markets, it is important to begin with a definition of the term. In most instances, site visitors and others have agreed that open access will be achieved when the provider promotes a philosophy of care that offers a comprehensive range of services using flexible, need-based admission criteria.

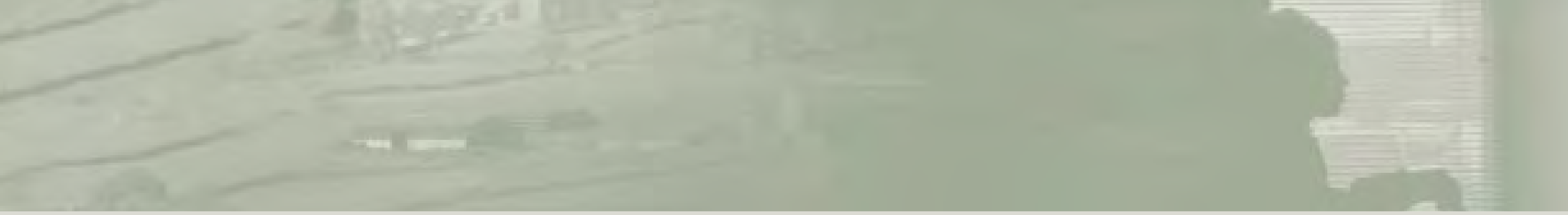
Open access, in other words, is the commitment to finding a way to admit any eligible patient with a progressive and/or life-threatening condition who wishes for and consents to care. For some hospice providers, this may mean re-thinking past practices about “appropriateness and readiness” for care and/or "acceptable” treatments. While the intent to offer an inclusive approach is important, making a decision to adopt this kind of outreach and service commitment can be challenging when fiscal and/or staff resources are limited.

Medicare hospice regulations do not define specific treatments as legitimate for hospice care or not, instead requiring the hospice to provide the appropriate palliative care necessary and reasonable to manage the patient's condition. Hospices with a commitment to open access have found that a willingness to provide, for example, radiation and chemotherapy, when appropriate may result in more and earlier patient referrals and the ability to "average" incremental costs across a larger caseload. However, smaller hospices may find the associated costs of more extensive and/or expensive interventions especially difficult to implement, having a size-based limit in financial risk tolerance.

In rural areas, open access raises particular dilemmas, not just because of the generally smaller caseloads but because there may not be another provider available to admit the patient if the hospice or palliative care provider cannot. The development of palliative care and the integration of services among providers offer new avenues to resolving the challenge of access. As an element of the continuum that can encourage open access, palliative care can offer needed services while also utilizing existing reimbursement mechanisms to extend area resources.

Despite recognized constraints, several of the sites visited are effectively extending services to a broader array of patients:

- At Hospice Care Corporation in Arthurdale, WV, Malene Davis reports that the adoption of open access reflects an expanded definition of the mission of her organization. The resulting outreach has made a big difference in the number of patients and families served and in the program's image in the community. Open access branding has encouraged staff to be more inclusive in defining admission criteria and care options. As a result, the census has grown dramatically and length of stay has increased.
- Hospice of North Iowa in Mason City, IA has expanded its reach by establishing service lines, including a community-based palliative care initiative and a developing hospital palliative care consultation service, in addition to its core business as a Medicare-certified hospice. The Star Care Program is one of the provider's innovative approaches to patient outreach. Initiated 3+ years ago, this venture is designed to provide home-based care for the chronically ill elderly who do not qualify for any other health care programs. Although the program was initially designed to address an unmet need, it has ultimately resulted in an increase in the hospice census.
- The community palliative care program of Hospice of Siouxland, Sioux City, IA, is described in Vignette 3.
- At Hospice and Palliative Care of Western Colorado, Grand Junction, CO, a conscious effort has been mounted to create a community presence that is broader than death-and-dying services. Three initiatives have been particularly helpful with this change: a dynamic program for children, extensive community grief support services and a public profile for the organization as a sponsor of fun events that people want to attend.



- At Central Vermont Home Health and Hospice in Barre, VT, a partnership between the home health agency and the hospice has enabled the development of a community-based palliative care program. The collaboration offers a bridge for those patients who choose to transition from home health to hospice or from hospice to home health. According to the hospice's Director, Diana Peirce, the relationship with the parent agency is outstanding. The home health agency has a history of careful expense management to constrain costs while encouraging increased market penetration. The access goal for this organization: "We want to make it easy."

Challenges of Creating Capacity

The goal of capacity building is to expand the definition of the market by becoming known for providing inclusive services to meet unmet or undermet needs. Many rural and frontier end-of-life providers have taken risks to increase capacity and service outreach. As a result, they better serve their communities. Rural and frontier providers identify three essential elements in developing the capacity of the program and the community to deliver and better utilize quality palliative and end-of-life care services:

1. Staff education and training to strengthen and develop the skills needed to broaden services;
2. Community education to establish a broader understanding of availability and opportunities for care and thereby increase utilization of the services; and
3. Outreach strategies to develop and sustain partnerships and collaborations and to sustain and grow expectations for hospice and palliative care services.

The first of these capacity-building strategies is discussed below while the second and third will be explored in Chapter 5.

Professional Education to Build Capacity

The following are practical examples of staff education, training and philosophy that rural providers are offering to create and sustain program capacity:

- Development and adoption of service performance parameters;
- Education of the board and/or local leaders on national trends such as palliative care, open access, managed care, chronic care management and the nursing shortage;
- Establishment of an ethics committee comprised of community members, hospital representatives, palliative care and hospice program staff, and church members to review specific ethical considerations/cases and to address projects such as advance care planning and advance directives;
- Importing best practices in enhancing service definition and outreach;
- Offering support for local and offsite continuing staff education and subsidies for staff to pursue relevant credentials;
- Appointing full-time or substantially part-time physicians and advanced practice nurses as soon as feasible and involving these individuals in professional and community outreach;
- Establishment of bridge programs and/or extended palliative home care;
- Improved/extended utilization of volunteers in meeting caregiving requirements. For hospices, this may include volunteer participation in providing continuous care as allowed by regulations; and
- As needed, referrals to other organizations. For example, Hospice of Anchorage, Anchorage, AK, a non-Medicare certified hospice, refers patients to the closest Medicare-certified hospice when appropriate.

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Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 5:

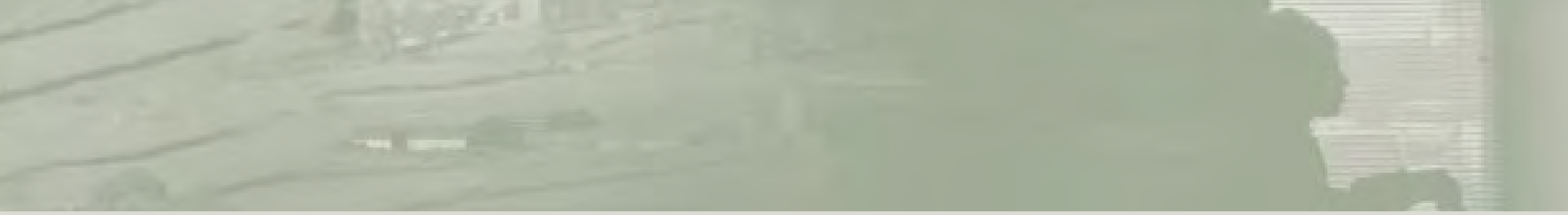
Getting the Word Out

Chapter 5: Getting the Word Out

Community education is particularly important for the hospice and/or palliative care provider considering venturing into new service arenas such as open access (described in Chapter 4). Community education ventures could include the following:

- Establish a community relations function within the organization. When resources allow, fund a position to provide outreach and education to service and community groups;
- Use staff and volunteers to establish a Speaker's Bureau to address community groups about the provider's services and to detail important related considerations such as advance directives and estate planning. For example, Hospice of North Iowa, Mason City, IA regularly offers staff speakers to make presentations on advance care planning, service availability and related topics;
- Borrow or create and distribute print material describing the services available to respond to the stated preferences and needs of the local market;
- Involve media outreach, which can include television commercials, radio broadcasts and newspaper articles. High Peaks Hospice in Saranac Lake, NY, is the focus of an annual Radio Day, during which all regional radio stations work together to create a full day of programming in support of the hospice. Listeners get information about the services the hospice offers, how to access those services, stories about unidentified patients and directions on how the community can contribute to the agency through volunteer services, employment, referrals and charitable gifts;
- Find creative ways to inform the community about hospice efforts. At Hospice of North Iowa, billboard space features a thank-you note from a grateful hospice family;
- Develop innovative fund-raising such as the effort at High Peaks Hospice, at which a local television station broadcasts video coverage of elementary school children who have successfully collected hospice donations;
- Encourage word of mouth and community involvement as keys to sustaining and enhancing growth. As noted by Jeri Stone at Sidney Health Center Hospice in Sidney, MT, “word of mouth and action create vision and passion”;

- Produce and distribute a newsletter. Hospice of the Plains in Wray, CO, distributes to 3,500 community members a newsletter that includes notes of thanks to volunteers and donors, information about upcoming fundraising events, poems, hospice happenings and recent grants to increase community awareness, involvement and investment with the program;
- Articulate and present a clear and positive image emphasizing the ways in which the palliative care and/or hospice program meets the needs of individual patients, families and the community at large. The language used should reflect input from local service users to assure that it is consistent with what the market wants rather than what providers think the market needs;
- Provide continuous outreach to physicians, advanced practice nurses and other health care providers;
- Promote and hold friendly fund-raising events that reflect favorite activities in the community. For example, the Montrose site of Hospice and Palliative Care of Western Colorado, Grand Junction, CO, holds a golf tournament once a year as one of its major fund-raising events;
- Hold thank-you events in the community for the community. The Plateau site of Hospice and Palliative Care of Western Colorado held a hoedown as a community appreciation event; and
- Provide readily accessible computer-based information to the community. Hospice of Anchorage provides web-based educational information free of charge.



Community Outreach

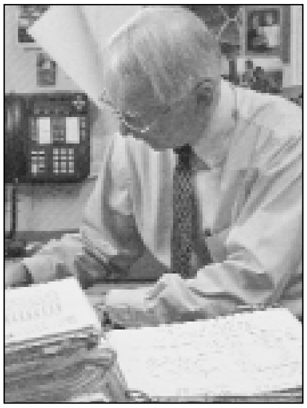
Beyond informing the community, effective program positioning involves collaborating and partnering with other organizations and active participation in local coalitions, committees and other initiatives. Examples include:

- Working with state organizations to identify and exploit opportunities to support palliative and hospice care;
- Becoming a visible presence at special events in the community and supporting the efforts of others;
- Running a local resale shop. Hospice and Palliative Care of Western Colorado and Hospice of the Red River Valley each operate a store called Heirlooms selling community-donated items. Store staff are mostly volunteers;
- Building and sustaining strong relationships, collaborations and partnerships with community members, service providers and other organizations to create a palliative care continuum. For example, the Alaska Native Tribal Health Consortium system must use non-tribal resources to increase care and reach those who need to be served. The consortium’s philosophy is that no one can meet all service needs independently; all must collaborate because resources are limited.

All of the above approaches create a “different” image. The provider becomes known in the community for the services it offers and for being a good team player, willing to contribute to and share in good outcomes.

Chapter 5: Getting the Word Out

Marketing

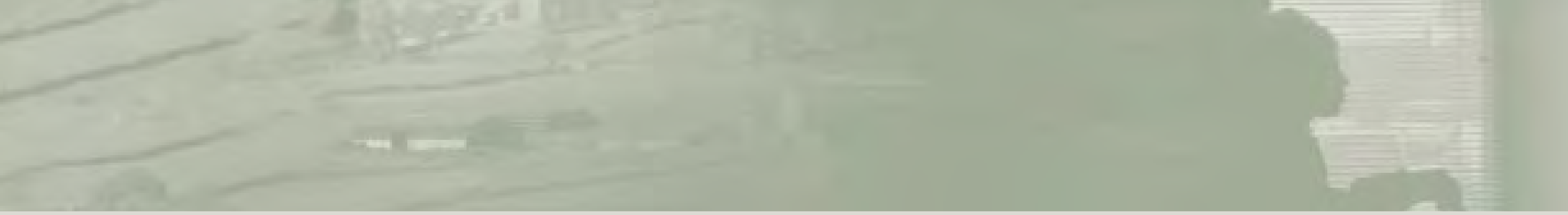


Identifying and communicating about the need for new and/or expanded programs are central to the theme of open access *(see also Chapter 4).* Effective marketing strategies are essential for both external and internal audiences and success depends on approaches tailored to targeted markets. While outreach to other providers is key, outreach and education for the general public is also essential. Many initiatives to address this audience were identified with the general themes of promoting access, community connection and visibility.

There are differences of opinion about the relative worth of formal marketing activities, probably reflecting variations between local cultures. While some programs allocate significant resources to traditional marketing activities, at least one respondent reports discontinuation of that effort and a re-focusing on less formal educational outreach as the preferred outreach strategy.

External Markets: Sites visited report that informing and involving the physician community is a top priority when an expanded definition of services is the goal. Identifying physician perceptions about current practices and proposed changes will dictate how best to encourage support and, where necessary, overcome resistance. Two challenges are to: (1) clearly define program services, and (2) overcome commonly held misperceptions. The CAPC website (www.capc.org) has a list of commonly held misperceptions about hospice, which could be a helpful tool.

Physicians who do not understand the roles they can play in palliative care and hospice deserve special attention. For example, in areas served by Covenant Hospice in Pensacola, FL, and Hospice of the Bluegrass in Lexington, KY, a number of physicians are recent additions to the community and have reservations (some voiced and some unstated) about losing their relationships with their patients and/or about the potential adverse impact on their patient revenue from hospice and/or palliative care program expansion. Clarification of the on-going role of the primary physician in care management can be addressed in simple written policies summarizing program intent. Identifying physicians who are comfortable with the relationship and having them communicate their experience to skeptical or resistant colleagues is another approach.



Addressing billing issues directly can also help overcome physicians' concerns. Three tools may be helpful for this:

- "Physician Billing — Palliative Care Consultation Patients," which provides a case example and cites the Medicare authority allowing two physicians of like specialty to bill on the same day with the same CPT code if they use different diagnoses (*www.capc.org*);
- "Billing Information for Primary Physicians of Hospice Patients," which provides a case example and cites the Medicare authority for a primary care physician not affiliated or under contract with the hospice to bill Medicare for services provided to a hospice patient (*www.capc.org*); and
- *Providing Direct, Billable Physician Services to Hospice Patients: An Opportunity to Upgrade the Medical Components of Care*, a technical assistance report from NHPCO illustrating how hospices have increased access and quality by employing salaried physicians and subsidized the cost by billing Medicare for the visits they make to hospice and palliative care patients (*www.nhpco.org*).

Outreach to providers other than physicians is also essential. Finding ways to collaborate effectively with hospitals in introducing, delivering and/or supporting inpatient palliative care services will help address the reality that there is a huge unmet need in acute care settings for expert pain management, symptom control, comfort and end-of-life care services. It is noteworthy that nationwide, 50 percent of patient deaths occur in a hospital setting. In addition to collaborating with inpatient palliative care services, assuring the availability of hospice care within the hospital can provide access for patients who otherwise might never realize this option. Clarification of the purposes and services of hospice and palliative care may also facilitate the discharge planning function.

To this end, shared staffing arrangements can sometimes facilitate improved patient outcomes while containing cost. When shared staffing is anticipated, a clear definition of roles and responsibilities will facilitate the connection. As an example, the CAPC website (*www.capc.org*) includes the job description for a Hospice Liaison Nurse, a position shared between several hospices and a hospital in Lexington, KY. Shared staffing and formal partner outreach agreements should be reviewed by a health law attorney. Note also that these documents must be tailored to reflect the provisions of state laws and regulations.

Site visit findings underscore the importance of optimizing patient services by identifying and maximizing all available community resources. In addition to physician and hospital relationships, connections with nursing homes, assisted living facilities, insurers, community agencies such as Meals on Wheels, disease specific associations and others can have a significant impact on patient care and community relationships.

Internal Marketing: The re-definition of clinical services packages and patient populations can be construed as an obstacle or an opportunity by staff. All respondents note the importance of assuring clinical competencies for new outreach efforts. As a result, much effort is focused on assuring that staff has the clinical competencies necessary to deliver newly designated or expanded services, so that the agency promises only those services that it can deliver effectively.

One of the more subtle issues in promoting program outreach may be overcoming staff resistance and/or misperceptions (see list of common misperceptions about hospice cited above). Managers report the importance of assessing current against preferred practices and intentional or unintentional resistance around revised definitions of admissions criteria and patient eligibility. Resistance may be particularly strong in veteran staff members, underscoring the need to offer targeted, on-going education and, when necessary, counseling.

Despite the fact that resistance to change may be a concern, the sites visited cited many examples of staff receptivity to new program outreach. Opportunities to enhance and extend services are generally well-received, with staff often assuming a leadership role in identifying under-served populations and unmet service needs and in helping to shape positive proactive responses to those needs.

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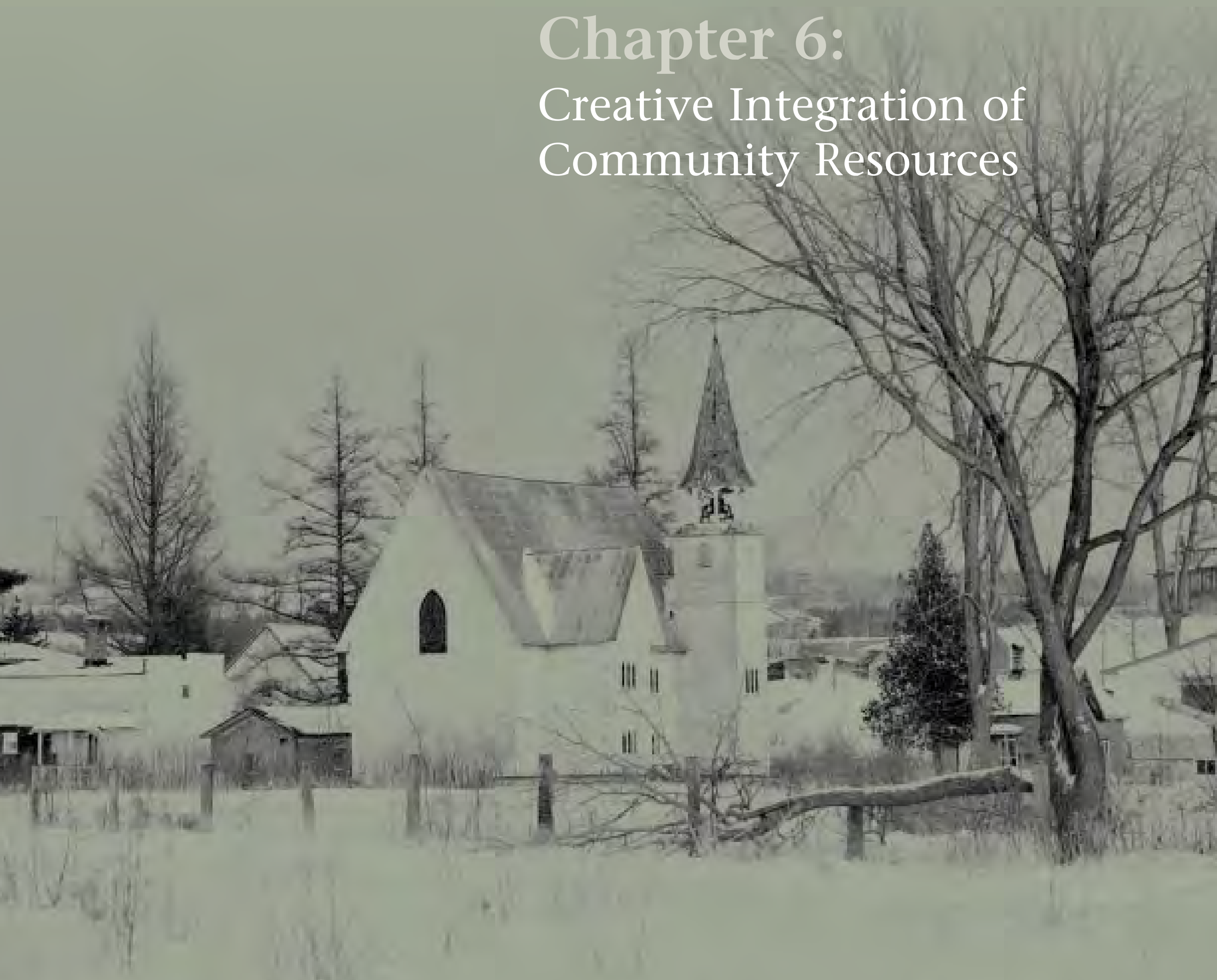
Chapter 6:

Creative Integration of Community Resources



Chapter 6: Creative Integration of Community Resources

Given the relative isolation and limited resources of many rural and frontier hospice and palliative care programs, collaboration with other providers and community agencies is essential. These partnerships can extend service availability, improve response time, foster local ownership of caregiving and serve as educational vehicles for optimal hospice and palliative care. Further, the projected aging of the population makes it clear that future service demands will exceed present capacity and require an even greater reliance on effective, efficient resource sharing.

In many rural and frontier areas, community resource integration is informal and largely based on personal relationships. In other settings, recognition of the advantages of community partnerships assumes a more formal structure. For example, grant support enabled Littleton, NH, to achieve designation as a Model Community. The project is based on a premise of collaboration across service lines with input and assistance from community volunteers.[12]

In Littleton, examples of shared services include an agreement by area transportation services and volunteers to assist people who need access to health care and a definition of specific outreach activities to mainstream those with a history of mental illness. The police participate in a Morning Wake-Up call program — checking in to make sure that patients living alone are contacted each day to determine if they are in need of assistance. An Area Resource Team facilitates outreach to elderly citizens; activities include cross-agency updating of lists of those at risk living in the community and administering a telephone network for coordination of needed services.

While the provisions of Littleton's Model Community grant are not limited to health care, the focus on shared resources creates an expectation that residents will recognize and address health-related needs. In addition, the grant underwrites an area needs assessment to provide some of the data necessary for health planning purposes.

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[12] The Model Community grant was awarded to the Town of Littleton by the New Hampshire Department of Health and Human Services and the University of New Hampshire Institute on Disability.

Partnerships with Other Providers

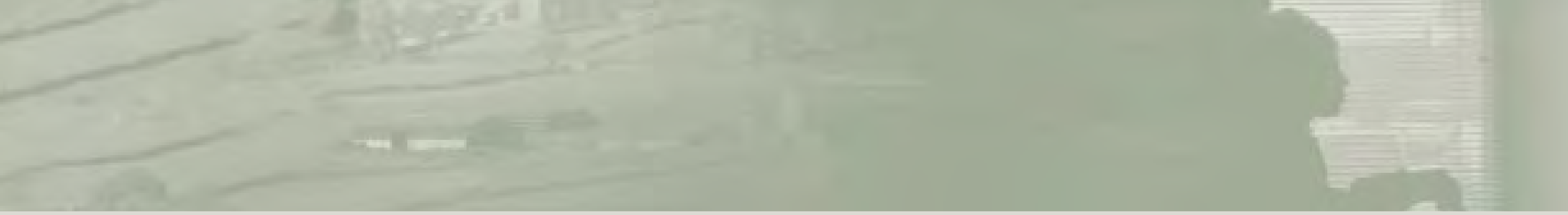
Partnerships between hospices and community-based palliative care programs and other area or regional health care providers include those with hospitals, home health agencies, nursing homes, assisted living facilities and pharmacies. For a fuller discussion of physicians' roles in rural hospice and palliative care and creative collaborations in obtaining physician involvement, ***see also Chapter 8 on p. 57***.

Partnerships with Hospitals: Partnerships between community-based hospices and/or palliative care programs and hospitals in rural and frontier areas have some unusual dimensions. Achieving smoother and more inclusive integration may be complicated by structural disincentives in reimbursement.

In some sites visited, for example at High Peaks Hospice in Saranac Lake, NY, inpatient utilization is higher than for many urban counterparts. The management of clinically complex cases in a setting far removed from inpatient access can be daunting and finding staff to provide continuous care for hospice patients with acute needs at home is sometimes difficult. Geography, climate and transportation challenges for staff and/or for patients and families may dictate an inpatient stay as the optimal site for service delivery, even if that would not be the patient's first choice.

Conversely, providers in other parts of the country such as Covenant Hospice in Northwestern Florida and Southern Alabama find that inpatient utilization is low, perhaps reflecting more readily available staffing and/or the preferences of primary physicians, patients and families. The sheer distance some rural and frontier patients have to travel to get to a hospital can be a disincentive to admission, as can the related inconvenience and expense for families members who want to participate in caregiving or visit the patient.

Hospices and community-based palliative care programs removed from urban settings are sometimes called upon to care for patients who receive out-of-area health care. For example, patients and/or families may choose to receive specialized medical services from a hospital at a distant location. Under these circumstances, it is not uncommon for patients to return to the rural or frontier setting with a plan of care that includes medications and/or interventions that are difficult if not impossible for the local provider to deliver, particularly in the absence of timely notification.



One approach to this problem is to create a working relationship with the distant hospital. For example, VistaCare patients from Hobbs, NM, may travel to Lubbock, TX, to access the services of a major medical center. A liaison nurse located at the hospital in Lubbock can coordinate case management from that site with the staff in Hobbs. This approach works well when the patient is known as a hospice patient — but not so well if that information is not noted in the chart. Other sites also incorporate the liaison nurse concept. In Lexington, KY, multiple hospices jointly fund the salary of a liaison nurse to fulfill the case management function for patients returning from the medical center to their home communities.

One stimulus encouraging the development of partnerships with hospitals is the growth in the number, size and scope of inpatient palliative care programs. In 1999 the American Hospital Association listed 237 of these initiatives; by 2003, 1089 were reported and the growth trend continues. Some community providers view the development of these inpatient programs as an opportunity for improved inpatient hospice and palliative care and for enhanced collaboration between the hospital and community-based partners. The Dartmouth-Hitchcock Human Caring Initiative is a developing framework to facilitate just this kind of connection.

Because hospices and community-based palliative care programs often have the necessary clinical expertise, there is a real opportunity for these entities to assume a leadership role in creating a continuum of palliative care services. The Palliative Care Center of the Bluegrass, established by Hospice of the Bluegrass in Lexington, KY, is one such example of a program established by a community hospice to provide consultations in local hospitals and a care continuum for discharged patients.

In other settings, the advent of hospital-based palliative care has been introduced without the involvement of established community programs. Under these circumstances, findings ways to bridge community and hospital-based services may be more challenging. By identifying the key players in the hospital initiative and proposing collaboration aligned with the goals of the inpatient effort, community-based programs can facilitate partnership opportunities. In all cases, physicians and hospital-based nurses play important roles in determining both the desirability and the feasibility of partnering, although the relative dearth of doctors and nurses trained in palliative care can complicate this connection.

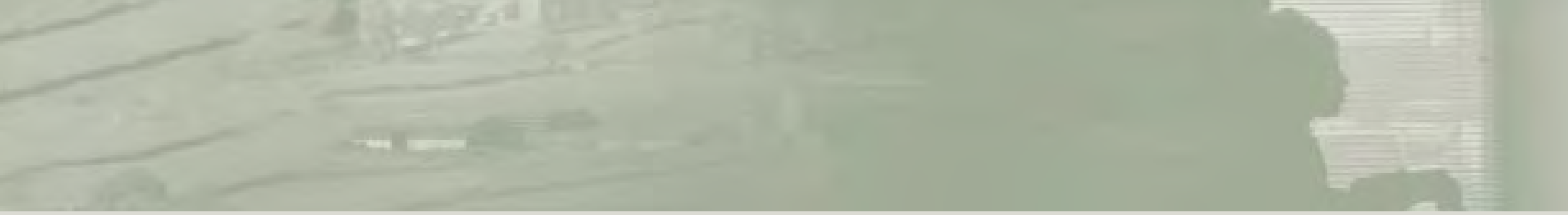
Another issue unique to rural and frontier settings is the growing use of Federal designation for Critical Access Hospitals. The defined payment structure and regulations for these hospitals shift the reimbursement mechanism from prospective to cost-based Medicare payments. The Critical Access Hospital program can shore up the local health care infrastructure and may give hospitals the needed financial breathing room so they can collaborate. However, special considerations characterize the relationship of Critical Access Hospitals and hospices. Prospects for addressing problems in the hospice/Critical Access Hospital interface, which may require legislative solutions, are being explored by NHPCO and the National Rural Health Association. ***A discussion of this issue can be found in Appendix B.***

Successful hospice and/or palliative care program partnerships with Critical Access Hospitals have been crafted by Hospice Care Corporation in Arthurdale, WV, Hospice of the Plains in Wray, CO, and at the developing palliative care initiative in Littleton, NH.

Partnerships with Home Health Agencies: The relationship between free-standing hospices and rural home health agencies varies from setting to setting. The existence of two separate entities can result in solid partnerships; however, it sometimes leads to competitive rather than cooperative outcomes.

Selected sites profiled in this toolkit are home health agency-based hospices. In some rural and frontier settings, this arrangement constitutes an important continuum of services reflecting the synergies realized from shared staffing and coordinated administrative functions. At Central Vermont Home Health and Hospice in Barre, VT, the two entities have created a palliative care “bridge” to connect with assisted living facilities and nursing homes. The number of palliative care consults is increasing as this service becomes better known.

Partnerships with Nursing Homes: In urban and rural communities, hospice care covered under the Medicare/Medicaid Hospice Benefit is provided to patients who have the nursing home as their place of residence. In many settings, cross-provider collaboration is valued and encouraged and partnerships between nursing homes and community-based hospices are



viewed as important access resources for patients who are eligible for hospice care. In addition, the partnership constitutes significant program enhancements — for both providers.

Particularly in settings where access to inpatient service is limited, hospice and/or palliative care support in the nursing home setting may enable residents to remain in their “home” as their disease progresses. Because staff retention in nursing homes is an issue in rural as well as urban areas, the expertise in pain and symptom management, as well as the supportive services provided by hospice and/or palliative care team members, can contribute to enhanced patient care as well as improved morale of nursing home staff.

In areas where provider competition is the norm, there are often barriers to the development of inclusive relationships between nursing homes and hospices or palliative care providers. This may be a reflection of payer disincentives or ongoing misunderstandings about the benefits and burdens of affiliating. Because both providers seek to provide the best possible care for patients within the constraints of limited resources, it is important to define partnership advantages in those terms.

It is sometimes useful for the non-nursing home community partner to offer bereavement support for patients, families and/or staff and continuing education opportunities as precursors to proposing a more fully integrated patient care partnership. Non-hospice palliative care units or consultation services are also being established in some nursing home settings.

Partnerships with Assisted Living Facilities: As a relatively new provider category, the assisted living facility offers a residential option for individuals who may need some help with activities of daily living but who do not meet the requirements for nursing home placement. As an example of such a partnership, the relationship between the Central Vermont Hospice and the Assisted Living Facility, both in Barre, is noteworthy. In this collaboration, special emphasis is placed on excellent pain management and support for terminally ill residents, who are able to live and die in place.

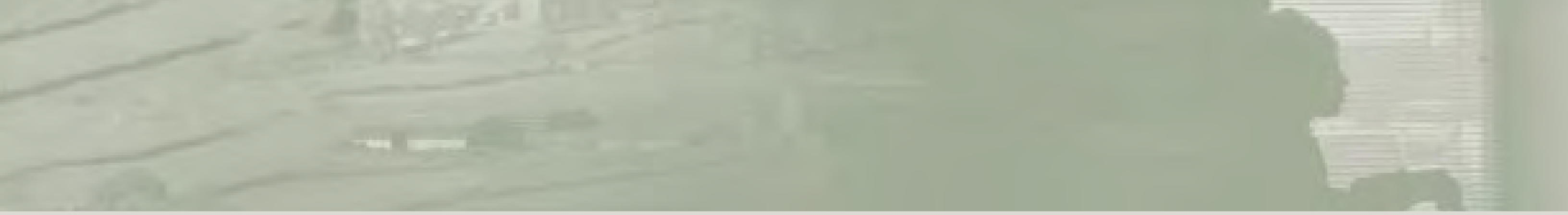
Most of the residents in these settings are local or family members of locals. The hospice can and does offer continuous care as needed in this setting and residents continue to receive medical care from their private primary care practitioner. Few third-party payers currently provide support for assisted living, so financing care in this setting is a significant issue. In Barre, the hospice subsidized the care of at least one homeless man who required this type of a living environment at the end of his life.

However, state regulations regarding assisted living facilities may preclude care for the patient whose needs grow more complex near the end of life. For this reason, providers must be cognizant about the regulatory considerations. It will be important to check with state regulations to determine whether assisted living facilities are able to continue to keep residents so that they can live and die in place. National groups representing assisted living interests are currently focusing on these concerns; additional guidance may be forthcoming in the near future.

Partnerships with Pharmacies: Pharmacy availability can be a challenge in rural and frontier areas. Often, the only pharmacy in town is open less than 24 hours a day. However, once the pharmacy provider commits to being available on an as-needed basis, effective working relationships can be defined. Some of the sites have selected area pharmacists based on positive past experience, a willingness on the part of the pharmacist to commit to supplying needed products 24 hours a day and a commitment by the hospice to supporting the local economy.

Other providers have elected to contract with national pharmacy purveyors, of which Hospice Pharmacia and HospiScript are most frequently named *(see Appendix E)*, with on-line responsiveness, price, staff educational opportunities and prompt service cited as strengths. One provider uses HospiScript to obtain discounts on drugs supplied through the local pharmacy. This approach allows pharmacy reimbursement from the hospice to stay in the local community and support local businesses. In return, the pharmacist is often willing to respond if needed in the middle of the night.

Another important approach to working with limited local pharmacy resources is to do careful planning to anticipate potential emergency needs. For example, several providers place



emergency medication kits in the patient's home, where this is permitted by state pharmacy board regulations. These kits, containing an emergency dose of several essential palliative care medications, allow the patient and family to begin pain or symptom control with nursing support over the telephone if the nurse's visit to the home requires extensive travel time.

Hospice of North Iowa in Mason City, IA, has a relationship with a PharmD who is a professor at the University of Iowa, about three hours away. The pharmacist is available to review all patients' medications as well as providing assistance with protocols, standing orders, preferred drug list and education to staff, physicians, nursing homes and others.

Additional Community Resources

Other Agencies: Most of the sites visited have solid relationships with area organizations such as the Area Agency on Aging, the Red Cross, the United Way, the Alzheimer's Association, local churches and other organizations such as long-term care coalitions. In some cases, members of these organizations have taken the hospice volunteer training course and provide direct or administrative services. In an interesting twist, VistaCare staff often volunteer for other agencies as part of their commitment to community service.

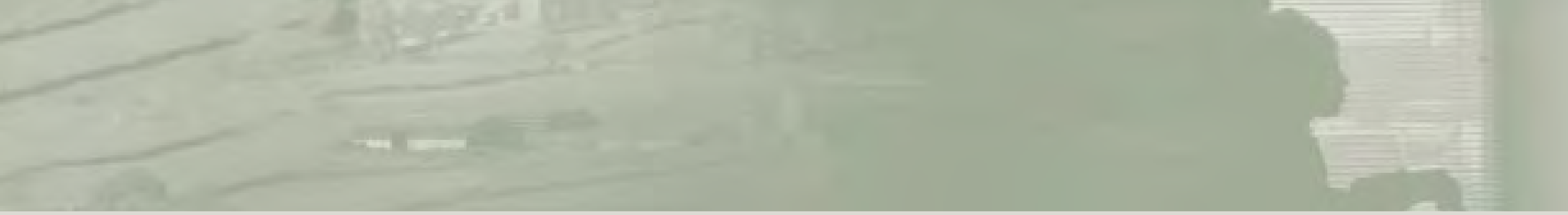
Participation in End-of-Life Care Coalitions: End-of-life care coalitions are formed by community members, health care providers and other organizations that come together to work to increase local awareness of end-of-life issues, especially regarding advance care planning, hospice care, palliative care and other end-of-life services. Coalitions work to identify community needs, advocate for changes in health systems and implement initiatives that provide information and support to dying people and their families.

Several providers participate with local and state end-of-life care coalitions. Prairie Haven Hospice in Scottsbluff, NE, started the end-of-life care coalition in its community, which now includes members who are educators, emergency responders, clergy, DME providers, nursing facility staff, mid-level practitioners, AARP staff, Health and Human Services staff, funeral directors, Red Cross, Alzheimer's Association staff and home health providers.

Hospice of Redmond, Sisters and Grant Counties in Redmond, OR, also created an end-of-life care coalition in its community. The goal of this initiative is to provide education and information to the community on end-of-life care, and to initiate a project of providing training in advance directives. Information on finding or starting a local or state end-of-life care coalition is available at *www.endoflifecoalitions.org*.

Governance Considerations: Community boards of directors represent another important mechanism for area outreach and partnership. The role of the hospice and/or palliative care program board appears to achieve its greatest impact for freestanding and home health agency-based providers, largely because these organizational structures offer the greatest independence in board recruitment, selection and education. Individuals who serve on rural and frontier hospice and palliative care program boards are likely to be visible and well-connected in the region and may also serve on the board(s) of potential or current health care or community agency partners.

During the site visits, several respondents underlined the importance of on-going board education to ensure accurate, current data as the basis for partnership outreach and development. However, there may be limited board educational resources in rural/frontier areas. Malene Davis, Executive Director of Hospice Care Corporation in Arthurdale, WV, uses the training CD, *How to Become a Great Hospice Board Member*, developed by Andrew Reed of Multi-View, Inc. (828/698-5885 or *www.multiviewinc.com*), to provide her board members with a general overview of their roles and responsibilities. In addition, this provider offers a carefully crafted annual training day to update all board members on issues specific to the region and the program.



Summary

It appears that the characteristics of successful and creative community connections in rural and frontier settings rest on integration with area values and mores. Trusted, visible leadership is essential, as is consistent delivery of high-quality services consonant with patient preferences and hardy staff who are prepared to embrace the challenges of caring for doggedly independent patients. Also needed are the communication skills to create and sustain effective partnerships with principals who are prepared to share authority and resources to achieve desired patient care outcomes.

Especially in rural areas, where resources may be limited, hospice and palliative care providers are well-advised to see themselves as community partners and team players, and to adopt an attitude of collaboration and multilateral enterprise.

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 7:

Financing

Chapter 7: Financing

All hospices and community-based palliative care programs face financial challenges as they strive to extend access to care for an increasingly complex case mix and/or reach out to the underserved. By definition of setting and payment formulae, providers in rural and frontier settings confront some unique obstacles.

Financing Challenges in Rural and Frontier Settings

A comprehensive paper by The National Rural Health Association, "Health Insurance Access in Rural America," provides insight into the special issues of its constituents, with important implications for hospices and palliative care providers and for health care policy makers.[12] This source indicates that:

- Although the number of Americans without health insurance continues to grow, rural and frontier populations are more severely affected by this problem.
- Despite the fact that rural and frontier areas have a higher percentage of people age 65 and older who qualify for Medicare, they still are more likely to be uninsured.
- Rural health care providers are in a different position from their urban counterparts in regard to serving the uninsured. Patients cannot be so easily turned away in rural settings where the selection of providers is much more limited. Many rural regions of the country do not have safety net providers eligible for public grant dollars to underwrite the costs of caring for the uninsured.
- Rural and frontier workers are often employed seasonally or part-time. Because of the nature of many rural economies, which are based on agriculture, mining, fishing or timber, rural employers are more likely to be small and less likely to provide health insurance.
- People from frontier areas are less likely to enroll in Medicaid because they tend to have less knowledge about the Medicaid program, are not as readily contacted by outreach programs and other social services as those who live in more urban areas, and may resist receiving this form of government support.

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[12] National Rural Health Association, Kansas City, MO: *www.nrharural.org/dc/policybriefs/insurance.pdf*.

Findings from the University of Minnesota Rural Health Research Center bring to light some additional considerations. In a paper entitled: "Are There Geographic Disparities in Out-of-Pocket Spending by Medicare Beneficiaries?" Radcliffe, et al., make the following observations: "Rural beneficiaries have, on average, personal characteristics that tend to keep utilization of health care lower. In addition, they are less likely to be minorities, less likely to be high school graduates, and they tend to live longer than their urban counterparts."[13] The study goes on to suggest that the lower use of services could reflect inability to afford care.

The median income for non-metropolitan elders from all sources is considerably lower ($9,229) than that of metropolitan elders ($10,351).[14] Studies also show that Medicare beneficiaries spend approximately 20 percent of their income out-of-pocket for medical expenses. However, the proportion of income required for medical care is significantly greater for low-income beneficiaries and rural beneficiaries are more likely to be low income. As an illustration of this trend, beneficiaries whose income fell below the Federal poverty level spent an average of 37 percent of their income on health care in 1997.[15] Given the exponential rise in health care costs since then, it is likely that out-of-pocket health care expenditures today are taking an even bigger bite out of low-income beneficiaries' incomes — a factor likely to further impede access to needed health care, with particular relevance for those living in rural and frontier areas.

For all of the reasons cited above, providers in rural and frontier areas must be creative in order to meet service expectations within the boundaries of financial responsibility. Sound business practices dictate maximization of third-party reimbursement, aggressive pursuit of philanthropic support, partnerships with volunteers and with other providers to extend the reach of services, and careful marshalling of resource utilization.

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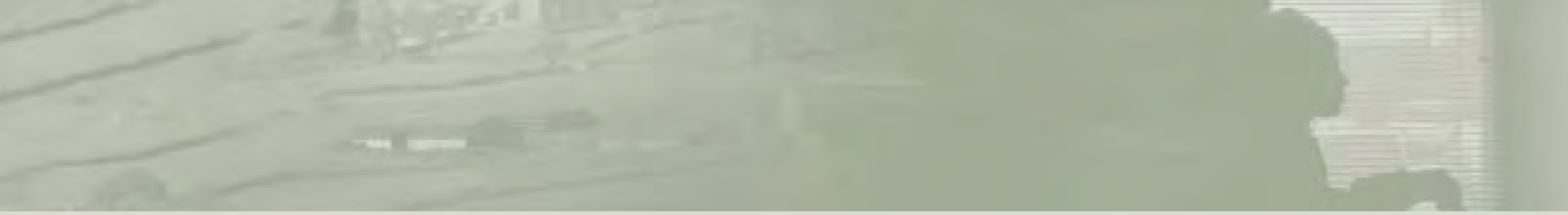
[13] Radcliffe, Davidson, Call, Dobalian. *Are There Geographic Disparities in Out-of-Pocket Spending by Medicare Beneficiaries?* Rural Health Research Center, Division of Health Services Research and Policy, University of Minnesota, Working Paper #49, October 2003. See www.hsr.umn.edu/rhrc/wkp_monographs.html. Coward, RT, Krout, JA, Eds. *Aging in Rural Settings: Life Circumstances and Distinctive Features*.

[14] Coward, RT, Krout, JA, Eds. *Aging in Rural Settings: Life Circumstances and Distinctive Features*. Springer Publishing, 1998.

[15] Radcliffe, et al.; see citation above.



Financing Considerations by Provider Type

Medicare-Certified Hospices: According to the Department of Health and Human Services,[16] overall Medicare hospice rates are lower for rural hospices than urban hospices despite the fact that actual costs of providing care are impacted by issues such as:

- Travel time (in terms of mileage and staff time);
- Less opportunity to benefit from economies of scale for such things as drugs and durable medical equipment; and
- Greater vulnerability to the impact of high-cost patients based on smaller volume.

NHPCO statistics indicate that 97 percent of all hospice providers are Medicare Hospice Benefit-certified.[17] Certification enables the provider to bill Medicare a flat amount for each day of care, at one of four levels of care — routine home care, continuous home care, general inpatient care or inpatient respite. The rate includes all services the patient may need, including professional staff, drugs, medical supplies and equipment. In states where the state Medicaid agency has added hospice to its list of optional services, certification also enables the hospice to bill Medicaid for services provided to eligible patients. To learn more details about the Medicare Hospice Benefit, ***see Appendix C***.

Medicare Hospice Benefit certification also serves as a condition of payment eligibility for many other third-party insurers. The Medicare designation is essential in hospice financing, as eighty-one percent of the patients served by hospices are 65 or older.[18] The Centers for Medicare and Medicaid Services report that in 2002, 661,462 patients received services through the Medicare Hospice Benefit, and a total of 37,333,045 days of hospice care were provided.[19]

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[16] MedPAC Report to the Congress: New Approaches to Medicare, June 2004, p. 147: *www.medpac.gov/publications%5Congressional_reports%SCJune04_ch6.pdf.*.

[17] *NHPCO Facts and Figures*. National Hospice and Palliative Care Organization, Alexandria, VA: *www.nhpco.org/files/public/Hospice_Facts_110104.pdf*.

[18] NHPCO Facts and Figures; see citation above.

[19] *http://www.cms.hhs.gov/statistics/feeforservice/HospiceUtil02.pdf*.

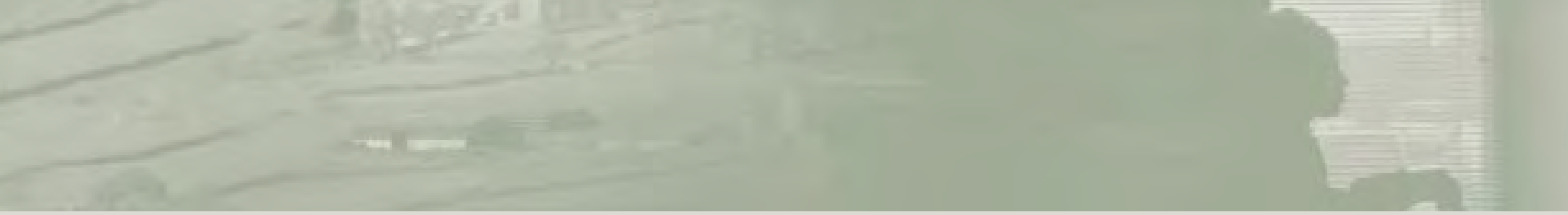
Billing for services provided by a hospice requires a computer system and access to the Internet, since most payers, including Medicare and Medicaid, require electronic submission of claims. In addition, a user-friendly information system is essential to track the patient care and service delivery information required for billing. Paradoxically, the very providers who are most dependent on prompt payments — small, independent programs — frequently have the least access to this kind of data support. Many of the sites visited noted shortcomings in information systems capabilities, which in turn impede timely, accurate billing for services.

Partnerships can bring added value in this area of technology to process and pay claims. Hub-based models like Covenant Hospice in Pensacola, FL, create linkages with local offices to enable access to sophisticated data management services that would otherwise be unavailable. The VistaCare Corporation provides its member programs with strong information services support. Home health agency-based models also realize the benefits of this resource sharing.

As payers, state Medicaid offices have been known to be slow to process and reimburse claims. This reality impedes cash flow and can create a significant barrier with nursing home partners who are reimbursed for hospice patient room-and-board charges after the hospice is paid by Medicaid. Aggressive pursuit of Medicaid claims payments through identification of, and regular communication with, designated state staff has yielded impressive results in recoupment of delayed compensation for High Peaks Hospice in Saranac Lake, NY.

Other third-party payers also pay for hospice services, usually following Medicare’s lead and paying on a per-diem basis. In most cases, the hospice or palliative care program will need to work directly with the case manager at the insurance company to determine exactly what services the patient’s insurance will include and how to submit claims. A strong collaborative relationship with Blue Cross and Blue Shield of Vermont and Eastern New York has resulted in a receptive climate and prompt consideration of billing from Central Vermont Home Health and Hospice in Barre.

Staff time is the most significant expense item in the hospice budget. For this reason, an assessment of staff productivity is important. This is another area where High Peaks Hospice is experimenting with a focused approach to tracking staff travel time using census and a distance modifier to attempt to describe an efficiency factor that works in a rural setting The



approach being tested rests on the assumptions that one hour of driving equals 30 miles and one hour of time equals $25. The intent of this measurement approach is to introduce a level of objectivity in defining the best possible use of limited resources.

Philanthropy is another important revenue stream for all hospice providers. Most rural and frontier hospices have exceptional relationships with their communities, and financial support has been forthcoming. These charitable dollars enable the underwriting of under-funded or unfunded services.

Volunteer Hospices: Volunteer hospices are another important contributor to end-of-life and palliative care. According to the Volunteer Hospice Network (*www.growthhouse.org/hospic/vhn.html*), there are 150 volunteer hospices nationwide. Because these entities do not choose to be Medicare-certified as hospice providers, they do not bill third-party payers for hospice services. However, they facilitate access to and/or see that services are provided for patients in their communities.

Volunteer hospices have been very successful in raising philanthropic support and often assist the work of other providers. In rural and frontier areas, this partnership often includes hospitals. A good example is the relationship between the New Hampshire entities Hospice of the Littleton Area, a volunteer hospice, and the Littleton Regional Hospital. The hospice focuses on community outreach and fund-raising to enable improved access to services and is an active participant in the developing palliative care initiative.

Palliative Care Services: Billing for community-based and inpatient palliative care services is already feasible under Medicare's Part B professional services codes. While the aim of palliative care is first and foremost to provide access to the best possible care for advanced and life-threatening illnesses, it is also true that effective pain management and symptom control can sometimes improve resource utilization.

Adding palliative care to a patient's treatment plan bridges many of the services found in inpatient and community settings. It helps to avoid duplication, create efficiencies and diminish waste. Palliative care often results in satisfied patients and families while demonstrating favorable cost comparisons to traditional care, particularly in the inpatient setting. Further, there is good evidence to support the contention that effective palliative care programs yield positive clinical results and increase the number of hospice referrals. For all of these reasons, developing palliative care bridges is an important agenda item.

Physicians, Nurse Practitioners and Advanced Practice Nurses: Partnerships with area physicians, physician groups, nurse practitioners, advanced practice nurses and physician extenders are important relationships in every community. For hospice services, physicians may bill for their services through the hospice program or through Medicare Part B, depending on the services provided and their relationship to the patient.[20] Nurse practitioners acting in the role of the attending physician for hospice patients are now allowed to bill for their services to hospice patients through changes enacted by the Medicare Modernization Act of 2003. A description of the new nurse practitioner provisions and how they can be used can be found at *www.nhpco.org*.

Data from the Center to Advance Palliative Care and elsewhere demonstrate the vital role of physicians and advanced practice nurses in improved care and increased hospice referrals from palliative care programs. For information about Part B billing for physician and advanced practice nursing services, see two documents on the CAPC website: "Billing for the Professional Services of Physicians" and "Billing for the Professional Services of Advanced Practice Nurses" (*www.capc.org*).

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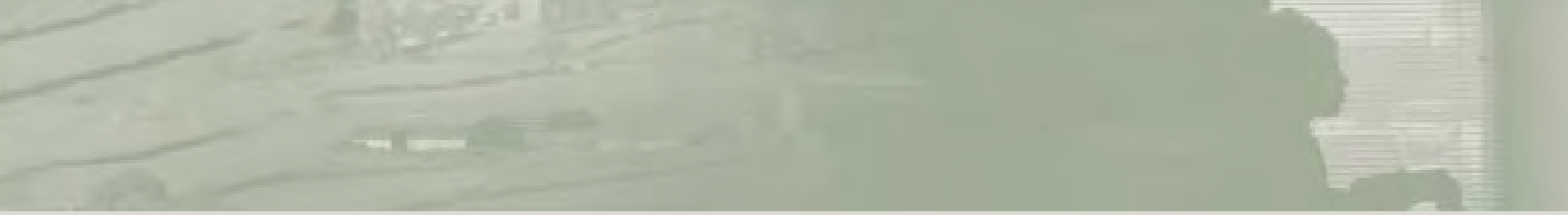
[20] *Providing Direct, Billable Physician Services to Hospice Patients: An Opportunity to Upgrade the Medical Component of Hospice Care. Alexandria, VA: National Hospice and Palliative Care Organization, Alexandria, VA, June 2003.*



MedPAC Rural and Frontier Financing Considerations: The Medicare Payment Advisory Commission (MedPAC) has reviewed the costs of providing health care services in rural and frontier areas and as a result recommended an increase in provider payment rates. It is important to note that special payment considerations are already in place for some rural and frontier providers such as Critical Access Hospitals and Rural Health Clinics. Home health agencies receive a case-mix adjustment and an outlier consideration for high cost patients.

The good news is that in Fiscal Year 2005, rural and frontier hospice providers will receive a modest percentage increase as compared to other hospices within the overall Medicare Hospice Benefit reimbursement increase, although this increment is not expected to overcome the existing cost differential. A careful cost analysis is needed to further study the financing needs of hospice and palliative care for patients in rural and frontier areas.

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Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 8:

Staffing

Chapter 8: Staffing

Staffing is an essential element of providing hospice and palliative care in rural and frontier areas. Rural and frontier hospices and palliative care providers confront a variety of staffing issues, from limited availability of qualified staff to difficulty identifying, providing and paying for professional education and training for current staff. The human resources challenges identified in our research include unique local circumstances as well as some more general considerations encountered by both rural and non-rural providers.

Rural and frontier providers describe many creative, practical approaches to staff recruitment and retention, dual role staff models, cross-training and trans-disciplinary training, physician support and organizational mindset.

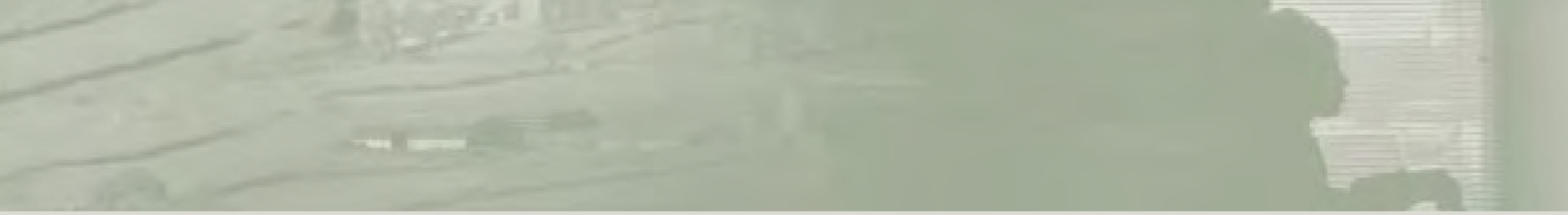
Staffing: Recruitment and Retention

Many rural and frontier providers experience difficulty in recruiting and retaining the needed complement of professional staff. The primary presenting problem in this arena is an applicant pool that is small to non-existent. In addition to limited numbers of applicants per position, there is a lack of qualified personnel, a paucity of individuals available to provide continuous care hours, reservations about working in hospice and palliative care, and a view by some potential candidates that hospice or palliative care on-call responsibilities are sufficiently stressful as to constitute a significant disincentive. Added to the limited applicant pool is the ongoing difficulty of competing with other area health care organizations or with neighboring urban areas on wage and benefit levels.

Although attracting newcomers to a rural area and growing the applicant pool may be a reality for providers located in resort areas such as Hospice of the Wood River Valley in Ketchum, ID, and High Peaks Hospice in Saranac Lake, NY, it is not a real solution for most rural end-of-life care providers. However, providers have developed other creative solutions to the challenges of recruitment and retention.

The list below describes the innovative ways in which some rural providers are addressing their human resource needs:

- Establish a reputation as a good employer doing work that is important to the community. In tight-knit communities, word of mouth is an important recruiting technique. Several informants noted that if the organization is known to be a good employer, qualified individuals will seek it out when looking for a position;
- Offer certified nurses aide (CNA) training — clinical and theory — as well as scholarships for CNAs to attend nursing school to advance on the career ladder;
- Provide education benefits to each staff member and, to the extent that it is feasible, offer reimbursement for the costs of attending educational conferences to staff at all levels of the organization, a practice followed by Hospice Services of Phillipsburg, KS;
- Offer mentoring programs through community colleges and pilot on-line programs such as the nursing educational affiliations crafted by High Peaks Hospice in Saranac Lake, NY. The mentoring program pairs a seasoned RN with a nursing student sitting for BSN certification; both the student and mentor get college credit for this effort;
- Establish a program to support staff health and wellness, such as the walking group established by Hospice Care Corporation in Arthurdale, WV;
- Provide stress management for staff, such as the program at Dare Home Health and Hospice in Manteo, NC, in which the only agenda at staff support and quarterly team meetings is to talk about work challenges. In addition, Hospice of St. Tammany in Covington, LA, offers individual stress management from a volunteer psychiatrist;
- Hold a yearly staff retreat, as does Prairie Haven Hospice in Scottsbluff, NE;
- Practice staff team building. The Cynthiana site of Hospice of the Bluegrass in Lexington, KY, assigns teams to make presentations on specific issues such as safety to the rest of the staff. An Academy Awards night is then held, at which the presentations are rated like the Oscars and the team voted the best gets a free lunch;



- Offer training to staff to add to their skill set. Hospice of the Plains in Wray, CO, provides staff training in speaking Spanish, as there is a growing number of Spanish-speaking residents in its rural community; and
- Encourage staff members to become teachers to families and other caregivers in caring for patients. Staff at Prairie Haven Hospice makes sure that patient and families have adequate supplies, empowers patients and families to care for themselves, and encourages greater use of the telephone.

The Social Work Challenge: Finding hospice social workers who meet Medicare requirements (a bachelor's degree in social work from a school accredited by the Council on Social Work Education) in communities where there is none in residence is a challenge with no easy solutions. Some hospices have tried to attract staff from outside the service area, but this approach is not always successful. Current regulations define social work as a core hospice service and require that the social worker be an employee of the hospice, which cannot contract for social work services.

New Conditions of Participation will not take effect for several years, as of this writing. NHPCO has reviewed the proposed Medicare Hospice Conditions of Participation, published in the Federal Register on May 27, 2005, with regard to the social work educational requirements. NHPCO will continue to advocate for a BSW educational requirement for social work because of the intensity of service needs and counseling requirements.

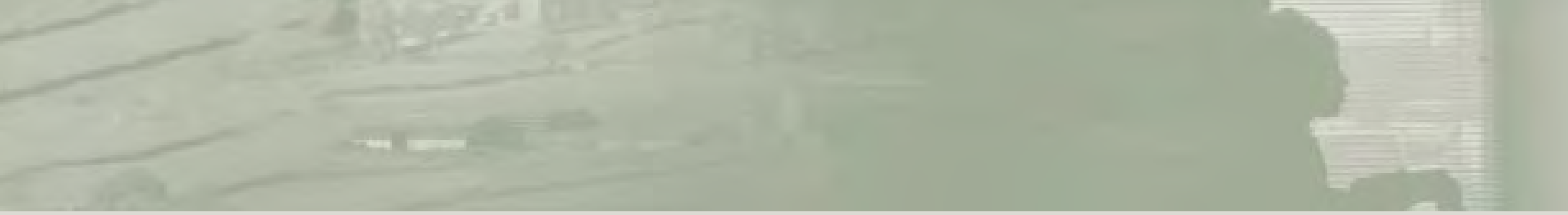
This may be an arena where partnering with other providers can help fill the service gap. For example, a qualified social worker who works for the local hospital, home health agency or nursing home may be able to work part-time for the hospice. Local community agencies and/or private practitioners may be willing to offer volunteer counseling hours to help meet local needs not provided by the social worker.

Staff Models: Dual Roles and Cross Training

Personnel demands create additional challenges, one of which is how to provide quality end-of-life care with less than optimal staffing levels — i.e., how to make do with less. The limited number of staff members itself creates problems for providers: what to do with staff hours when census fluctuates? How can staff members get up-to-date training off-site if there is no back-up for them to be away from the agency? Practical realities dictate that in some cases when staff members have dual roles, they are less able to devote the time needed to master each one, which in turn may impact on the quality of the services.

Providers are finding creative solutions to provide quality end-of-life care services with fewer staff:

- Employ part-time staff whose primary salaries are derived from other jobs;
- Avoid requiring field staff to go to the office every day, since the real focus of their work is visiting patients, wherever they may be;
- Define staff positions to include multiple roles;
    - If the provider has multiple sites, employ a business manager/volunteer coordinator (full or part-time) for each office;
    - Recruit volunteers to do the majority of fundraising under staff direction;
    - Have the Executive Director also serve as the Volunteer Coordinator, as is done at Hospice of the Plains in Wray, CO; and
    - Use the social worker (if available) to do admissions, coordinate bereavement services, contact pastors, work with chaplains in all counties, and facilitate grief support groups, community grief and bereavement support and counseling, a model offered at Hospice of the Plains.



Creative Teamwork

- Assign a specific staff member as Nursing Home Coordinator or hospital liaison to strengthen relationships and coordinate patient care;
- Assign one nurse to a specific geographical area to encourage continuity and productivity;
- Given sufficient volume, establish specialized teams such as a Nursing Home Team, Assisted Living Team and Home Care Team, an approach that has worked well for Hospice and Palliative Care of Western Colorado;
- When possible, encourage joint nurse and social worker visits to patients to increase productivity and team relationships; and
- Hire nurses specifically for on-call coverage.

Physician Availability: Community physician support for the rural hospice can be another staffing challenge. One provider noted that the only physician in town is not a hospice supporter and, therefore, many eligible community members are denied hospice services. Employing medical directors for hospice and/or palliative care programs also presents unique staffing challenges for rural providers, since physicians usually have their own practices and have limited time to offer to other duties. Frequently, medical directors can only devote one to two hours weekly to the hospice and/or palliative care program, mainly to attend interdisciplinary meetings and give orders via telephone.

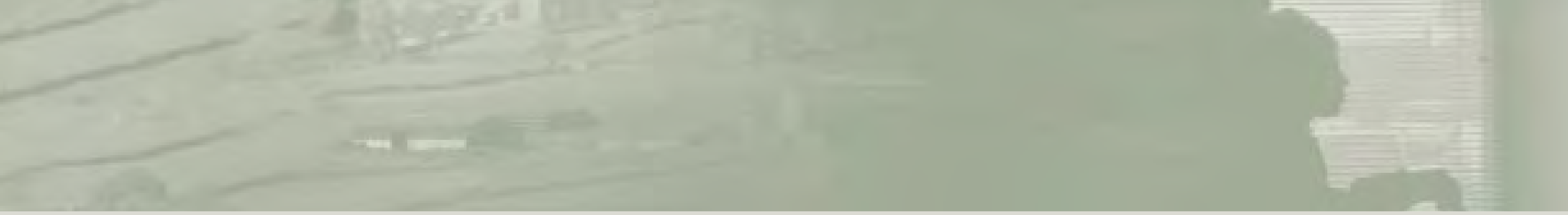
If the rural hospice is not able to hire its own physician, it may need to partner with medical staff from a local hospital or clinic, perhaps even creating a shared position and then working jointly on recruitment, retention and training. Providers in rural and frontier areas have found other practical solutions to these issues:

- Where possible, hire a physician trained in hospice and palliative care medicine or identify a licensed practitioner willing to gain the necessary expertise and then find and support training opportunities;

- Encourage local physicians (including the hospice and/or palliative care program medical director) to become board-certified in hospice and palliative care;
- Involve the hospice or palliative care physician in community and professional outreach and education to raise awareness of end-of-life care issues and the organization's services;
- Employ incentives to encourage the hospice medical director to be actively involved with the interdisciplinary team. For example, at Hospice Care Corporation in Arthurdale, WV, medical directors are paid a minimal amount to be active participants with the team; and
- Explore the potential of telemedicine/telehospice as a way to make the best possible use of limited physician resources ***(see also Chapter 10)***.

Physician's Assistants, Nurse Practitioners and Advanced Practice Nurses: These practitioners have the potential to expand the clinical reach of rural hospice and palliative care providers, particularly in communities where rural clinic-based physician extenders are already in practice.

One example of this collaborative approach is Hospice of the Wood River Valley in Ketchum, ID, which facilitates coordination with two rural clinics in adjacent but mountainous counties that are too remote for its staff to visit in person. The Ketchum hospice has provided hospice and palliative care training to the staff of those clinics and also provides ongoing telephonic consultation and support to help them manage the care of terminally ill patients in their communities — where a physician may be on site in the clinic only once a week.



Staffing: Individual and Organizational Mindset

The organizational mindset common to these rural and frontier providers is to find and use creative strategies to meet staffing challenges. An organizational commitment to comprehensive caregiving; to providing adequate staff training, resources and benefits; and to being a mission- and value-focused organization all encourage staff retention and recruitment. Rural providers have learned that the interdisciplinary team is a strong approach both for the patient and family and for the staff.

Keeping a focus on collaboration and avoiding boundary issues between staff disciplines are important to ensure the synergy required to best address patient needs. The dedication level of all staff needs to be high in the rural setting, as highlighted by Jessica Hood from VistaCare in Hobbs, NM, who said, “We really rely on staff who are mission-driven.”

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Chapter 9:

Volunteers: The Heart of Hospice and Palliative Care

Chapter 9: Volunteers: The Heart of Hospice and Palliative Care

It is often said that volunteers are the "heart" of hospice and palliative care, providing a special kind of dedication, personal attention and human connection inaccessible to employed providers. While hospice and palliative care professionals are responsible for addressing specific concerns such as pain and symptom management (physicians and nurses), counseling and accessing community resources (social workers, chaplains and bereavement counselors), or personal care (certified nursing assistants or home health aides), the volunteer is called upon to provide "everything else" that isn't covered in professional roles but still is essential to promote comfort, dignity and emotional well-being for patients and their families. In many communities, nurses, physicians and other health professionals generously give their time as professional volunteers to provide expertise and advance the mission of the organization.

Roles and Opportunities

Volunteers are used in a wide variety of roles reflecting the community's needs and resources. Successful rural hospices and palliative care programs define roles for their volunteers consistent with local customs and culture. They then cultivate community awareness of the opportunities to volunteer and contribute to the mission of promoting comfort and dignity for patients and families in the community. Rural providers sometimes will call the patient's nearest neighbors to help out with specific, urgent tasks — but always with the patient's prior consent. (*See Appendix A* for a discussion of boundary and privacy issues.)

The most familiar role for volunteers in hospice and palliative care is that of a friendly visitor to the patient's bedside, sitting quietly or talking about whatever is on the patient's mind, with an emphasis on being present. Such visits may also provide respite for exhausted family members to rest, get out of the house and take a break from caregiving.

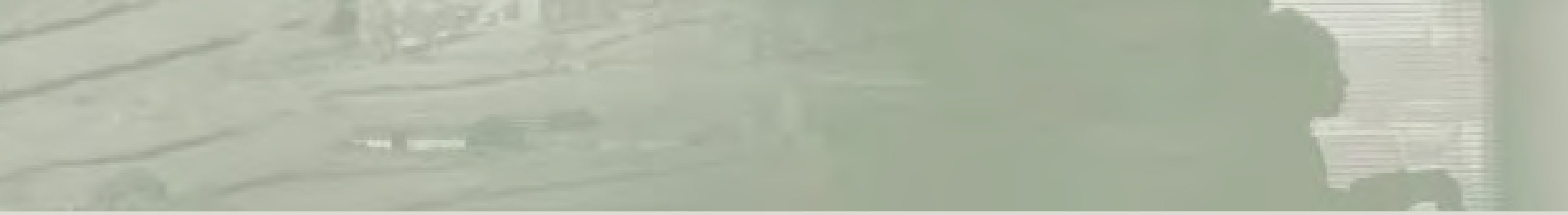
Other volunteers provide a host of practical supports such as gardening, housecleaning, meal preparation, baby-sitting, errands, rides to medical appointments, deliveries, translation, massage therapy, pet therapy, music therapy, visits to nursing homes, shifts on an inpatient unit and, where appropriate, bereavement support. Volunteers provide valuable services in the agency's office, answering the telephone, preparing mailings and performing various other clerical and administrative functions. For some hospices, volunteers do the lion's share of fund-raising, marketing or public relations activities under the direction of a staff member.

Challenges of Volunteer Management

The evergreen challenges of volunteer management for hospices and palliative care programs include recruitment, training, mobilization, scheduling, communication, supervision, debriefing and emotional support for the volunteers who extend the work of the interdisciplinary team. Community education and volunteer recruitment are year-round activities, even if the agency only offers its volunteer training program once a year. Small hospices have explored creative approaches to volunteer training such as collaborating with a local community college extension department or offering a joint training course with several neighboring providers.

Other current issues for volunteer management identified in the surveys for this manual include:

- The aging of the rural volunteer workforce;
- Particular difficulties in recruiting male volunteers;
- Lack of public transportation alternatives for volunteers — particularly those who are no longer able to drive;
- Bringing volunteers together for training, supervision and support when they must drive prohibitively long distances;
- Celebrating the role of the volunteer and finding ways to facilitate volunteers' enthusiasm;
- Identifying and addressing liability requirements and restrictions;
- Addressing potential problems related to patient privacy, which may be exacerbated in communities where "everybody knows everybody";
- Identifying sufficient volunteers belonging to the same local community as the patients the agency serves;
- Retaining volunteer involvement through fluctuation of census; and
- Competing with other opportunities for the volunteers' time.



Solutions

Rural hospices serving large geographical areas need to find a balance between identifying volunteers who live near the patients' homes while also providing sufficient service distribution, centralized management and supervision. E-mail is becoming an important supplement to the telephone for quickly sharing important information and helping volunteers experience a continuing connection with the program, even when they cannot be physically present in the central office.

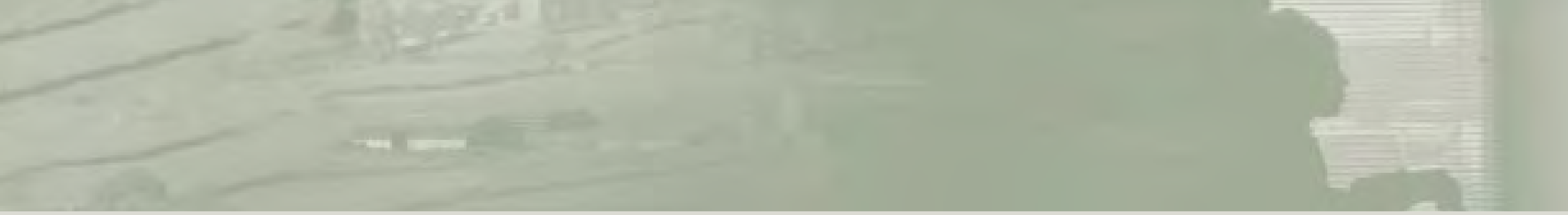
Part-time volunteer coordinators based in satellite offices or program managers who also function as volunteer coordinators can make a significant contribution to sustaining and enhancing the volunteer pool. It may also be possible to use seasoned volunteers to help supervise and manage other volunteers in their immediate area. Identifying volunteers who have specific skills in areas such as marketing and fund-raising can help to extend the reach of the hospice or palliative care program in those areas.

Hospices and palliative care programs are exploring new and more flexible approaches to identifying and mobilizing volunteers in the community. Traditionally, some providers required their volunteers to have free daytime hours, because that was assumed to be the greatest need and the easiest to manage. Additionally, volunteers were required to make a minimum time commitment for at least one year. Today's volunteers, however, demand greater flexibility and responsiveness to their current realities, including the option of one-time or time-limited assignments. Scheduling the volunteer coordinator's job to include some evening or weekend hours may also help to manage this increasing demand for flexible timeframes.

Faith-in-Action, a program of the Robert Wood Johnson Foundation to encourage formation of groups or faith-based caregiver teams (*www.fiavolunteers.org/*), has been a fertile opportunity for volunteer recruitment. In some cases, the provider may delegate some of the scheduling, support or other volunteer management responsibilities to the faith-based group.

Rural Volunteers Are Used in Varied Ways

- Hospice of the Red River Valley, Fargo, ND, with five regional offices, has a development committee with volunteer representatives from each local community who participate in fund-raising activities for that office. Ad hoc groups in several small towns also plan annual golf tournaments to benefit the hospice.
- When Hospice and Palliative Care of Western Colorado was starting out, there was no staff for marketing or fund-raising. Executive Director Christy Whitney called on representatives of local businesses and health care marketing firms to serve on the hospice's Marketing Committee, which tackled a different segment of the market each month. The hospice's first fund-raising gala was planned entirely by volunteers, including friends of Whitney's who responded to her specific requests for help.
- Hospice of the Wood River Valley in Ketchum, ID, has volunteers with financial expertise who help patients and families deal with financial issues (such as straightening out a mound of unpaid bills accumulated during the crisis of the patient's illness). Three volunteer members of the hospice's Board of Directors also serve on an investment committee to make prudent decisions on investing donated income above what is needed for current operations.
- New volunteers for the Ketchum hospice receive 24 hours of basic volunteer training. After a year of service they can be selected to receive additional training to become part of the hospice's crisis response team, which answers emergency calls day or night from first responders throughout the county.
- Hospice of the Bluegrass, headquartered in Lexington, KY, has used volunteer medical directors since its early days, although it now also employs full-time physicians. More than 40 volunteer physicians from all of the hospice's seven regional offices offer their services one or two hours per week to staff hospice interdisciplinary team meetings and assume attending responsibilities for patients who are referred without a primary physician. Importantly, they carry their hospice experience back to their medical practices and colleagues.
- The governance of Central Vermont Home Health and Hospice in Barre includes 14 to 18 members, many of them survivors of hospice patients. Every meeting begins with an "issue discussion" designed to challenge assumptions and educate the volunteers about important strategic considerations.



- The Barre hospice also utilizes volunteers to help fill out the schedule of continuous hospice care (which needs to be at least 50 percent nursing) for patients experiencing medical crises in the home. Hospices exploring the development of residential hospice cottages may also look to volunteers scheduled on shifts to help make such programs feasible.
- Some hospices have utilized teen volunteers in various capacities, including visiting patients or baby-sitting the children or siblings of hospice patients. Increasingly, schools and colleges are adopting community service requirements for their students and hospice can be a popular choice if the experience is well designed and presented. Hospice and Palliative Care of Western Colorado utilizes juveniles in the criminal justice system who are diverted from detention in a special program that requires them to perform community service.
- For some hospices, including Hospice of the Wood River Valley, the executive director plays an important role in interviewing and screening volunteer candidates in order to ensure their appropriateness for the work. A thorough screening process gives the agency more confidence in delegating responsibility to volunteers. Many states now require a criminal background check for hospice volunteers and, even if these are not required, many providers now pursue such reviews of all patient care volunteers. Each state hospice organization will know how to access the relevant regulations for its state.
- Hospice thrift or resale shops, such as those of Hospice of the Red River Valley or Hospice and Palliative Care of Western Colorado, make use of large volunteer crews to staff and operate the store, although employment of a professional store manager to direct the volunteer efforts is ideal.

Volunteer-Intensive Hospices

Some rural hospices describe themselves as *volunteer-intensive*, meaning that they have a significant volunteer workforce to staff many of the agency's essential activities, in some cases including nurses, social workers, chaplains or physicians acting in their professional capacities on an unpaid basis. Health professional volunteers can help the hospice to balance its budget with a more comprehensive level of professional services. In some states, hospice licensure laws have defined a category for volunteer hospices while some volunteer hospices provide volunteer and unreimbursed services under contract with a Medicare-certified hospice program, helping the Medicare program to meet its statutory mandates.

Integrating and balancing volunteer and paid professional roles requires a skillful touch by administrators, given the differing expectations, availability and commitment of unpaid helpers. The transition from largely volunteer-intensive to paid professional staffing is a milestone that also needs to be handled carefully if the agency wishes to retain the support and spirit of its volunteers. Some paid hospice staff may also contribute some of their time to the agency as volunteers, often in a different role than their salaried position. Careful attention to wage-and-hour laws will dictate the volunteer roles that paid staff may assume.

Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 10:

Technology

Chapter 10: Technology

Advances in technology create opportunities to increase the availability and accessibility of hospice and palliative care for rural and frontier citizens. For rural providers, the importance of technology lies in its potential to improve communication and documentation of access and quality. More communications with staff, patients or families and between providers help to ensure the provision of quality, effective services to rural communities. Telemedicine, or *telehospice*, refers to use of the telephone, telecommunications-ready in-home monitoring devices and other communication tools, including web-based capabilities. As a result of encouragement from the Federal Centers for Medicare and Medicaid Services, home health agencies have assumed a pioneering role in this type of outreach.

The majority of rural hospices and palliative care providers have yet to fully utilize the potential of computers or other technology. Providers attribute the limited use of new tools such as laptop computers for computer-based charting or videophones for home monitoring to the following challenges: technical shortcomings, lack of resources to purchase needed hardware and software, financial constraints that have limited their use of computer-based charting, hesitation experienced by patients and families in adopting e-mail as a form of communication, and limited access to computers.

Providers that have overcome these challenges and begun to adopt telehospice are utilizing the following:

- Information technology, data gathering and computers for laptop charting. These technologies have proven to be time savers, improving the ability to share information among professional caregivers and providing the documentation essential for timely, accurate billing;
- Family communication through websites, such as a program offered by Hospice of the Bluegrass in Lexington, KY, called Care Pages. This is a secure website for families to write updates on patients' progress and other information for family members who may be unable to visit or who live out of state;
- Cellular telephones, which are becoming common as many types of communications networks are now available and accessible. However, many rural and frontier areas still have significant geographic regions without cell towers, resulting in vast "dead" areas.

Chapter 10: Technology

Although the majority of the rural and frontier providers interviewed for this manual are not utilizing telemedicine/telehospice, research on new telehealth resources and end-of-life care providers who are using those resources has shown that telemedicine/telehospice increases communication with staff, patients and caregivers, decreases costs of care, and increases the effectiveness of end-of-life care services. An understanding of telemedicine/telehospice will demonstrate these advantages to its use and help reduce staff resistance to incorporating this technology to expand services.

Telehospice: What Is It?

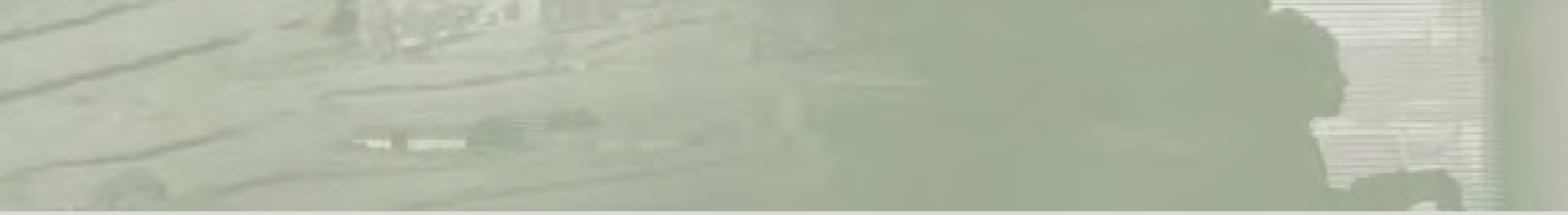
Telemedicine/telehospice is using forms of communication such as the telephone to extend end-of-life care services to those in need, ensuring access and service delivery. There is a common misconception that telehospice will replace visits from staff. In fact, this is not true. Hospices should continue to provide the services necessary to patients and families on site. Telehospice is intended to be used for extending what a program and its staff already does. It can be affordable and easy to use, and can provide additional support and education to the patient and family to supplement face-to-face visits.

As described in *Telehospice: A Resource Manual for Program Development and Implementation,*[21] technology can improve end-of-life care service delivery. For example, Good Shepherd Hospice in Hendricks, MN, a town of approximately 700 people, reports that telemonitoring in home and hospice care has changed the agency's model of care by enabling nurses to manage hospice patients more proactively than in the past and has enhanced the agency's means to care for patients and their families. Telehospice supplements the ongoing visits made by staff and may target the nature of the visit.

Telehospice: Starting a Program

How do rural and frontier end-of-life care providers take advantage of technology and, by doing so, increase access and expand services to their communities? The University of California-Davis received a Promoting Excellence (RWJF) grant for "Improvements in End-of-Life Care for Selected Populations" identified as underserved. One of the underserved populations was isolated rural communities. Three rural counties were selected and palliative care and telemedicine experts at UCD helped to develop, train and support

[20] *Telehospice: A Resource Manual for Program Development and Implementation,* by Audrey Kinsella with contributions from Barry B. Cepelewicz, Joan Haizlip and Lisa Van Dyck. Information for Tomorrow…telehealthcare program research and planning services, July 2004. Order from the NHPCO Marketplace at 800/646-6460.



hospice/palliative care development in those communities. This project identified key ingredients essential for hospice and palliative care providers to begin using telemedicine:

- Regulations concerning the provision of telemedicine/telehospice for the Medicare population;
- Staff acceptance, technical skills with the equipment, advocacy for the project and the ability to explain it to patients;
- A staff champion for the program;
- An understanding that telehealth is intended to augment, not replace, face-to-face health encounters, as well as an understanding that not every patient will want to use it; and
- Research on possible partnering and funding opportunities to assist the provider in establishing a telehospice program.

Telehospice: Reasons to Use It

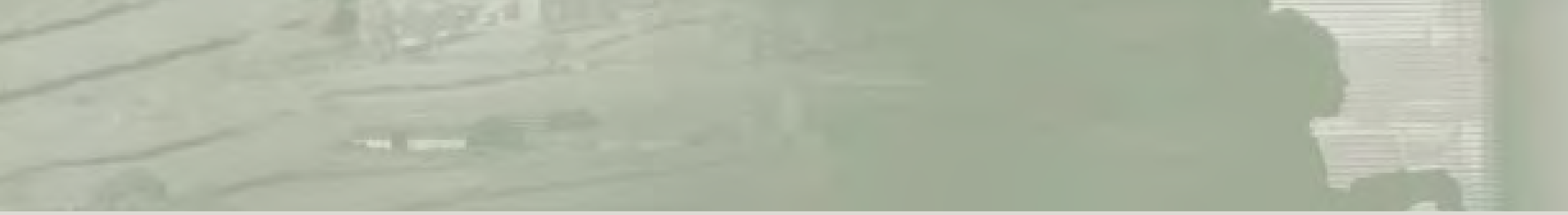
The use of telemedicine/telehospice is significant to providers in rural and frontier areas because it has the potential to:

- Address staffing and geographical challenges to expand the services that are already being provided;
- Increase the quality and effectiveness of care through additional tracking of vital signs, symptom management, provision of support, education and reassurance to patients and caregivers;
- Increase contact between staff and patients and caregivers;
- Offer access to specialists at a medical center, who may have greater familiarity with conditions and symptoms that are rarely seen by the local community practitioner;
- Create access to social work consulting services; and
- Utilize video teleconferencing to provide multi-site, interactive, case-based learning.

Telehospice Tools: What to Use

There is a range of tools that can be used to complement conventional care services. Some patients will do better with some tools rather than others, while other patients may need a variety of tools to assist them. Some options include:

- Telephones, telecommunications-ready monitoring devices, videophones and other telecommunications-ready tools to supplement the range of end-of-life care services provided;
- Telehealth workstations that are used either with live video or with a connection to a phone jack to obtain and transmit a range of the patient's physical data, sending it to a central nursing station for more regular monitoring;
- Individual measurement devices with telecommunications-ready capabilities, such as a blood pressure cuff, blood glucose meter or pulse oximeter;
- Videophones, telephones with visual capabilities that allow the patient, caregivers and staff to speak to one another and see each other for assessment, teaching opportunities and support;
- Preprogrammed devices for delivering clinical care such as infusion needs for pain medications; and
- Audio and video tapes for educational, supportive or stress relief purposes.



Telehospice: What Is Needed

Some steps should be taken by the organization before buying tools and implementing a program. These steps include:

- Analyzing the program services already being provided. This analysis ought to include review of the costs of those services and their effectiveness. The results can assist in the development of a telemedicine/telehospice program that is appropriate for the provider organization;
- Designing policies and procedures to ensure that the hospice continues to provide the services required to meet Federal and state regulations and that telehospice services are used properly and that the programs maintain proper functioning;
- Providing training for staff to ensure that appropriate and effective use is made of communication tools;
- Orienting patients and caregivers to the tools so as to ensure understanding and promote use of the communication tool;
- Assessing the patients' and caregivers' needs and circumstances in order to ensure that an individualized communication tool is chosen; and
- Identifying resources to lease/maintain equipment.

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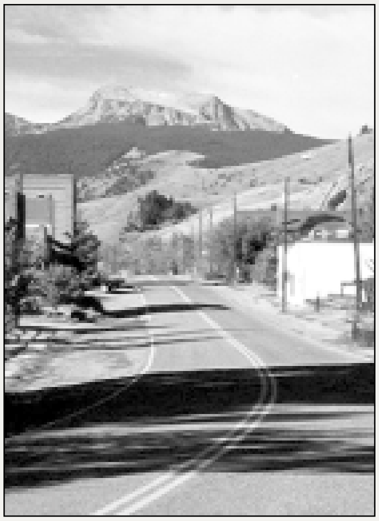
Chapter 11:

Special Area Considerations

Chapter 11: Special Area Considerations

As we explored in Chapter 2, there is no single, universal definition of "rural" when it comes to the provision of hospice and palliative care. Most often a combination of factors shape and define the agency's experience and the ability to overcome challenges of rural care delivery. One of those factors is population density, which is reflected in the critical mass of potential patients for community-based services. Another is the sheer "windshield time" that hospice/palliative care staff must spend driving between patients' homes, especially for providers that can serve regions of 6,000 or more square miles. These and other issues must be taken into consideration when planning for the provision of hospice, palliative care and bereavement support in rural areas.



Transportation Barriers: The condition of the roads is as important as actual mileage and these conditions may change with the seasons and factors such as snowfall, flooding and seasonal storms such as hurricanes or tornadoes. On the prairie, patients may be an hour or more apart on accessible paved roads, while in more challenging terrain patients closer in miles may be more distant in driving time. Other examples of transportation challenges include:

- Gravel roads that give way to dirt roads or cow paths;
- Sheep, cows or slow-moving farm equipment that may have right-of-way and block the roads;
- The challenge of providing on-call coverage across large geographic expanses;
- The potential for driving long distances and breaking down on dark, isolated roads at night;
- Difficulty finding some isolated homesteads with unconventional addresses or idiosyncratic directions;
- Absence of public transportation options, which limits patients, families and staff to private automobiles;

Geographic Isolation Issues:

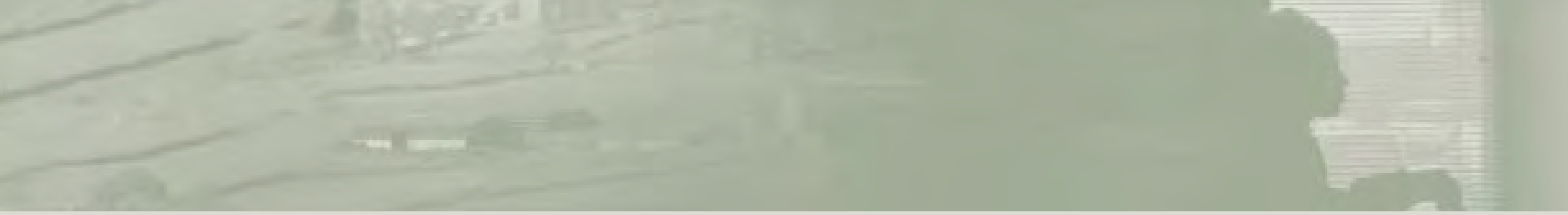
- Isolated patients living without electricity or plumbing in a much-loved but rustic personal dwelling or a hunting or fishing cabin;
- Geographically isolated patients who live alone;
- Hospitals and nursing homes located long distances from patients' families and communities;
- Spotty cell phone coverage, as well as POTS ("plain old telephone service") that may limit access to e-mail or the Internet;

Demographic Issues:

- The aging of rural communities, in some cases reflected in higher poverty rates, limited economic opportunities and the aging base of potential volunteers;
- An out-migration of young people seeking job opportunities and an in-migration of retirees, resulting in an increase in older residents far removed from extended families that otherwise might participate in their care;

Other Challenges of Rural Geography:

- State statutory requirements limiting who is allowed to pronounce deaths in community settings;
- Pharmacy and DME (durable medical equipment) services that vary widely in terms of coverage, hours of service and availability of unusual medications and preparations;
- Higher winter Worker's Compensation claims in snowbound communities due to shoveling and slips and falls on icy surfaces;
- Summer heat conditions that are life-threatening for elderly patients;
- All of these geographical challenges need to be revisited when it comes to providing bereavement support for isolated family survivors.



Rural residents understand the geographical and climate barriers and challenges. They have learned to cope with the isolation and with living some distance from medical specialties or other services. As a result, our respondents report, rural families may have tempered expectations for response times from distant providers, and may be more open to planning ahead as a way of framing care plans.

What can the team devise long-distance when it is just not feasible to make a home visit? Learning to be efficient and to get the most out of each visit, with more planning and consultation done by phone, is key. Rural providers emphasize educating family caregivers on dealing with contingencies while also carefully prioritizing the use of limited staff resources.

Creative Responses to Geography

Rural hospices and palliative care programs have addressed the full range of America's landscape features in caring for patients who live on mountains, islands, swamps, deserts, even, as in rural Alaska, in places that are accessible only by air. Providers have used ingenuity and creativity in crafting realistic solutions to these inevitable geographic barriers. Creative approaches and techniques utilized by hospices and palliative care providers serving rural areas include:

Wintertime Responses:

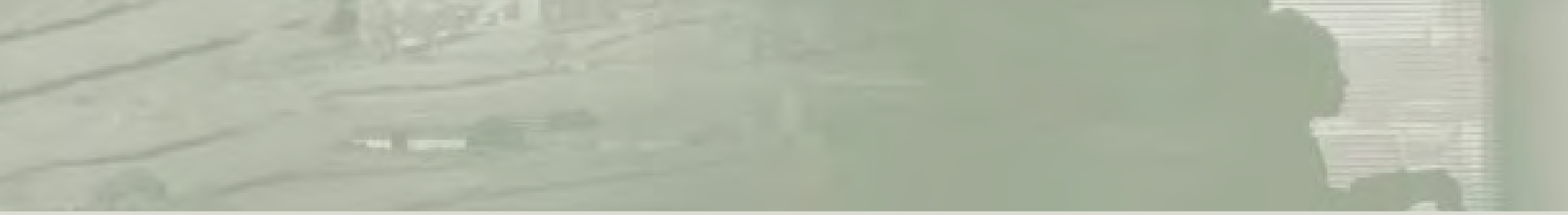
- Health care professionals serving areas with significant snowfall carry a snow shovel, blankets, boots, a bag of sand or cat litter (to aid in traction on icy surfaces) and even snow shoes in the trunks of their cars, while scheduling their time with the understanding that snow and ice will delay arrival.
- Others have used snowmobiles to reach isolated patients, while in some locales four-wheel drive is a must. Hospice Care Corporation in Arthurdale, WV, makes four-wheel drive vehicles available to staff for home visits during inclement weather.
- A head bolt heater or other means of warming the car engine on a cold day and access to a snow blower in order to be able to get out of the driveway as soon as the snow plow makes the highway accessible are other winter strategies.

Summertime and Hurricane/Tornado Responses:

- Weather-related caregiving challenges are not limited to winter snow. Summer hot spells can also be life-threatening for elderly patients. Under these circumstances, an air conditioner or electric fan may be an essential piece of medical equipment. The team's contingency planning should include ways to deal with geographical barriers imposed by hurricanes, tornadoes or flooding.

Flexible Staffing Responses:

- There may be an expectation that hospice field staff is "tough enough" to deal independently with unexpected circumstances, and that employees need to own a vehicle capable of getting where they need to go. However, not all staff will have access to needed transportation.
- Every agency handles on-call differently, reflecting landscape, staffing and other resource issues. Some hospices divide on-call between field staff and others hire designated on-call staff, paying up to a full-time salary for the availability to respond to after-hours emergencies. Some programs divide their service area into smaller on-call territories closer to staff members' homes; others assign on-call staff to the entire service area. In the latter case, a system of triage and secondary on-call back-up may be helpful.
- Some providers rely on part-time staff, each serving a smaller area, and develop virtual alternatives to having employees report to the office in person every day *(see also Chapter 8)*.
- Other approaches include trading caseloads and creating an emergency protocol for phoning every patient when weather conditions make home visits infeasible.
- Covenant Hospice in Pensacola, FL, has a sophisticated telephone tree for its entire staff, tested annually, to ensure that someone from the agency knows where every staff member and patient is supposed to be for after-hours emergency calls and in inclement weather such as the hurricanes of 2004.



Planning for Contingencies:

- Adequate agency planning and policies for addressing disasters (including earthquakes, floods, hurricanes, tornadoes, blizzards, chemical spills, fires or acts of terrorism) are also important. Many hospices have experienced such disasters and witnessed their impact on service delivery.
- Planning for contingencies may include ascertaining up front the patient/family's access to alternate sources of heat, water, power and oxygen for emergencies.
- Rural providers cite the value of developing close working relationships with fire, police, highway patrol, road maintenance departments and other first responders, so that they know who to contact with a request for help or special consideration in reaching the home of a terminally ill patient.
- Hospice of the Wood River Valley in Ketchum, ID, provides telephonic consultation for patients living in adjacent counties that are too far for the hospice team to make home visits, working with physicians assistants in the clinics in those communities and coordinating plans for home discharge and access to donated medical equipment that is maintained in a barn by a local service organization.
- Non-emergency medications can be mailed to patients and an "emergency kit" or "STAT box" containing small doses of a half-dozen medications most likely to be needed in a crisis can be issued to each new hospice patient on admission, if this is allowed by state pharmacy regulations. If it is a long drive to deliver a prescription, a family member could be asked to meet the nurse at a convenient crossroads to help expedite access to the medication and minimize staff transportation demands.
- Telemedicine, discussed at greater length in Chapter 10, also offers real potential for using professional resources more effectively.

Transportation Approaches:

- Given the impact of rising gas prices, some hospices have worked with area suppliers to get preferred bulk purchase consideration. Providers have indicated a desire to authorize higher mileage reimbursement rates but feel constrained by the reality of staff tax liability if payment exceeds the level authorized by the Federal government.
- Keeping the gas tank closer to full is advisable for on-call staff that may need to drive long distances at night when gas stations are closed.
- GPS (global positioning systems), not yet regularly used by rural and frontier hospices and palliative care providers, may well become standard equipment in the future.

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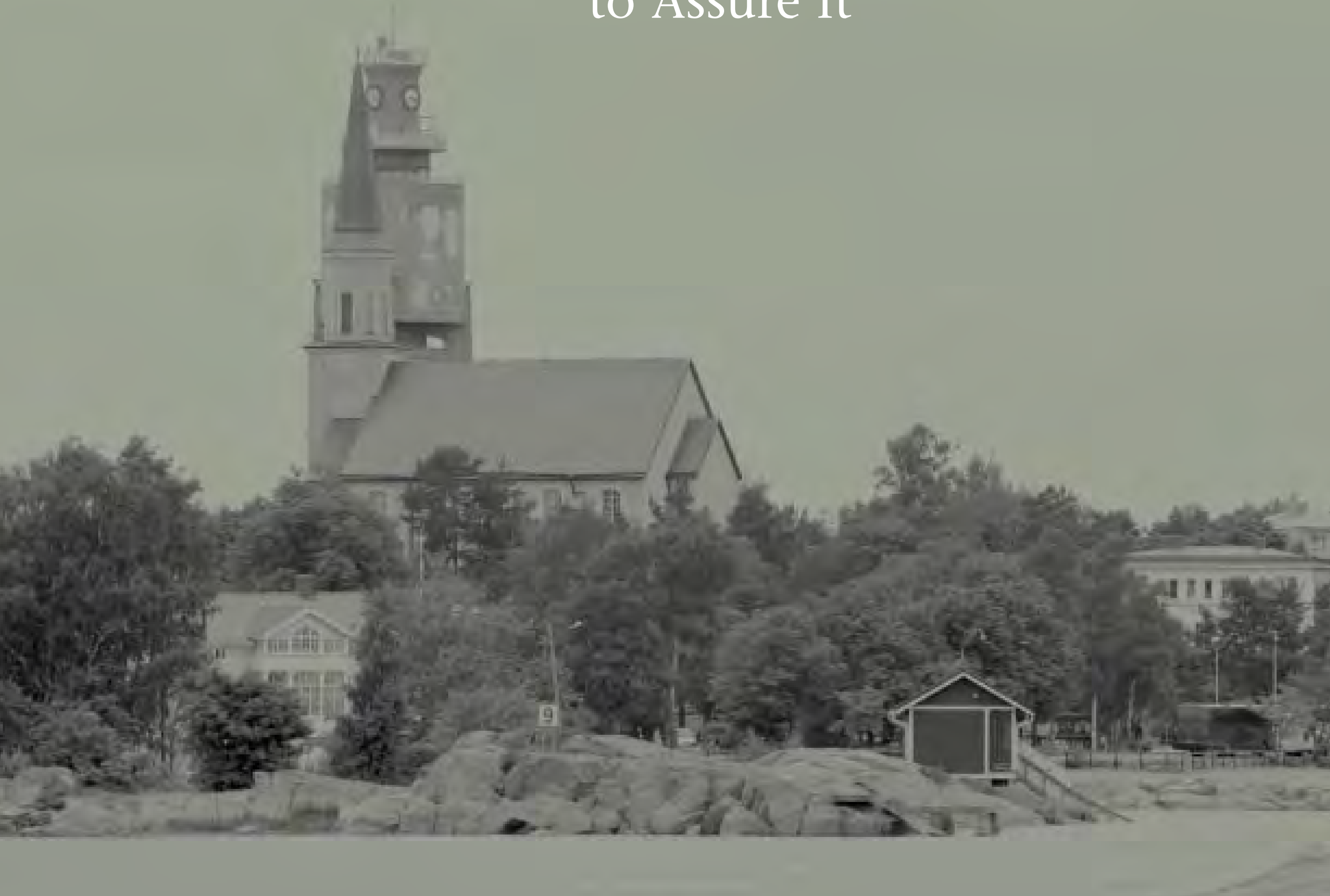
Chapter 12:

Quality and How to Assure It



Chapter 12: Quality and How to Assure It

The Institute of Medicine in 1990 defined quality of health care as: "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." The quality of care and services delivered to patients is a defining factor for any health care provider. Quality is often defined in terms of *outcomes* of process, clinical practice or structure — the actual, measurable results of the provider's services in terms of the lived experience of the patient.

In November 2004, the Institute of Medicine published a report on rural health, Building a 21st Century Community Health Care System in Rural America.[22] In this report, the IOM summarizes almost all of the rural healthcare issues of the past two decades. It also introduces new insights and recommendations in the area of workforce, quality improvement infrastructure, finance, and health information and communication technology. The report advocates for the development of rural systems of care designed for high quality and realizing the goals of healthcare. It also shows how the rural sector can exert quality leadership and advance the national quality improvement movement. It opens the door to rural engagement with the national "quality establishment," and creates new opportunities for resources. Hospice and palliative care programs can and should be part of the recommendations from the Institute of Medicine.

Quality in End-of-Life Care

Looking at quality in hospice and palliative care programs should be a comprehensive process, with clinical and administrative assessments. NHPCO is launching a quality initiative to assist providers with "doable" efforts to improve quality and consistency in care. Quality indicators will include, but are not limited to, compliance with state and Federal regulations, ethical business practices, assessment of success in meeting standards of care, patient/family satisfaction and employee satisfaction. More information will be available in 2005.

Two documents form the cornerstone for quality initiatives in end-of-life care — the *NHPCO Standards of Practice for Hospice Programs* and the *National Consensus Project Guidelines for Quality Palliative Care*. The NHPCO standards, first developed in 1979, undergo continuing review, with several chapters reviewed, field tested and re-released each year. Chapters cover access, rights and ethics; bereavement

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[22] Building a 21st Century Community Health Care System in Rural America, Institute of Medicine, 500 Fifth Street NW, Washington, DC 20001, November 2004. Available at *www.iom.edu*

care and services; clinical care and services; coordination and continuity of care; human resources; interdisciplinary team assessment and care planning; leadership and governance; management of information; performance improvement and outcome measurement; safety and infection control; and a special section for hospice inpatient facilities. The complete hospice standards document was last published in 2000 and will be completely up to date in 2005. This new version will be available for download from the NHPCO website at www.nhpco.org.

The National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* was published in April 2004 after more than two years of collaborative work by representatives of the five leading organizations in hospice and palliative care — the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, the Hospice and Palliative Nurses Association, Last Acts Partnership and the National Hospice and Palliative Care Organization. The clinical practice guidelines were created to build consensus concerning the philosophy, definition and principles of palliative care; to create practice guidelines that describe high-quality palliative care services to patients and families; and to broadly disseminate the guidelines so that current and future programs can develop their services with the guidelines as the guide.

The guidelines have eight domains and are based on the *NHPCO Standards of Practice for Hospice Programs*. They include structure and process of care, physical, psychological and psychiatric, social, spiritual, religious and existential, cultural, the imminently dying patient, and ethics and law. They can be downloaded from the National Consensus Project website at www.nationalconsensusproject.org or purchased from the NHPCO Marketplace.[23]

Making Quality a Central Business Plan

The importance of quality issues can be restated for any hospice and/or palliative care administrator or board member, rural or not, in the following way: *How do you satisfy yourself that your agency consistently provides a level of quality care desired by your patients and families, responsive to their real needs and to the larger community's need for access?* Since quality in health care is a national imperative, what can small or rural providers do to meet the demands of quality — measuring, tracking, totaling and evaluating how they define quality, and then using the results to drive improvements?

Three national accreditation programs currently survey hospices (Joint Commission on Accreditation of Healthcare Organizations, Community Health Accreditation Program and Accreditation Commission for Health Care), providing a vehicle that can promote quality. The accreditation process is voluntary and helps agencies

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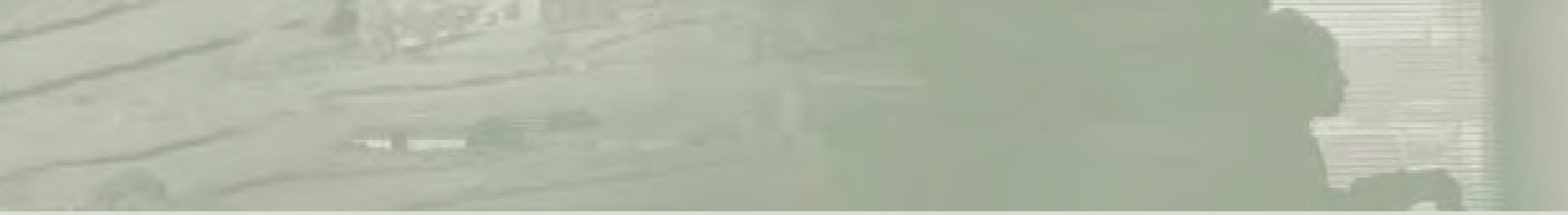
[23] NHPCO Marketplace can be reached at www.nhpco.org or by calling 1-800-646-6460.



of all sizes address clinical and administrative processes in a consistent way. The accrediting process provides recommendations for improvements that can be implemented by the organization's staff following the survey.

For organizations with limited resources, quality improvement initiatives need to be simple, workable and meaningful. Some providers have elected to begin the process by assessing pain management — one of the most important patient concerns in palliative and hospice care. Providers can track pain assessments using a standardized pain tool for every patient at defined intervals. Using the process specified for comfortable dying in the NHPCO Outcomes Forum (*www.nhpco.org*) is one place to start. This focus also presents an excellent opportunity for collaborating with other health providers on a local "Pain as a Fifth Vital Sign" initiative that seeks to institutionalize pain assessment community-wide.

Is Quality Measurement Different for Rural Providers?

Based on site visits and other research conducted for this manual, we are not aware of quality measures specific to the distinct challenges and settings of rural and frontier hospice and palliative care providers. Tools for the measurement of quality used by providers, regardless of setting, might include:

- **NHPCO's National Data Set**, which compiles demographic data on hospice patients and is currently collected by more than 800 hospice providers throughout the country. The aggregated data provide a yearly benchmark of a variety of demographic, length-of-stay and cost measures for participating hospices;
- **NHPCO's Family Evaluation of Hospice Care**, used by more than 350 hospices each quarter. Participants send the standardized questionnaire to families after the death of the patient to assess their satisfaction with the care their loved one received. It is widely used as the industry standard for measuring families' satisfaction with hospice care;
- **The Missoula-VITAS Quality of Life Index**, which was one of the first tools aimed at measuring the actual, self-defined experience, holistically defined, of dying patients and remains an important example of quality measurement specific to end-of-life care, although it is not widely used in current practice;
- **Performum, Multi-View, Inc.**, the **Population-Based Palliative Care Research Network (PoPCR**N) at the University of Colorado, and **Solucient**, a VH A company, among others, offer benchmarking programs that allow providers to compare their performance data in standardized formats with their peers. The programs are in current use by many hospices but not yet by a majority of the field;

- Sampling of customer perspectives by other means, including through organizations' broader needs assessment or strategic planning projects or via basic market research with referral sources by marketing staff — such as routinely surveying families, physicians, referral sources and other "customers" with simple satisfaction tools; and
- Indicators of financial performance — although financial indicators used by hospices are far from standardized at this time. Other specific quality tools used by rural hospices and palliative care organizations ***can be found in the Attachments section of this manual (Appendix G).***

Although the measures may be the same, there are some important differences in how rural or urban providers approach the challenge of measuring quality. For rural providers:

- Given smaller numbers of patients, it may be possible to collect and process data using existing staff;
- The smaller number of team members may find it easier to define and institute quality initiatives;
- Important work can be done on a small scale by ad hoc quality teams focused on "What can you improve by next Tuesday?"[24] Trial initiatives can be tested to encourage and support and measure improvement;
- Benchmarking parameters may be different for rural hospices (e.g., staffing levels, average number of visits reflecting greater driving time, staff mix), although in recognition of this fact the existing national benchmarking firms encourage comparisons between programs of like size and model; and
- In some rural communities, literacy or language levels may pose a barrier, such that the hospice may want to administer its family evaluation surveys by telephone rather than mail. Or, it may want to engage leaders in the community to help identify ways to perform a survey if translation or cultural issues must be considered.

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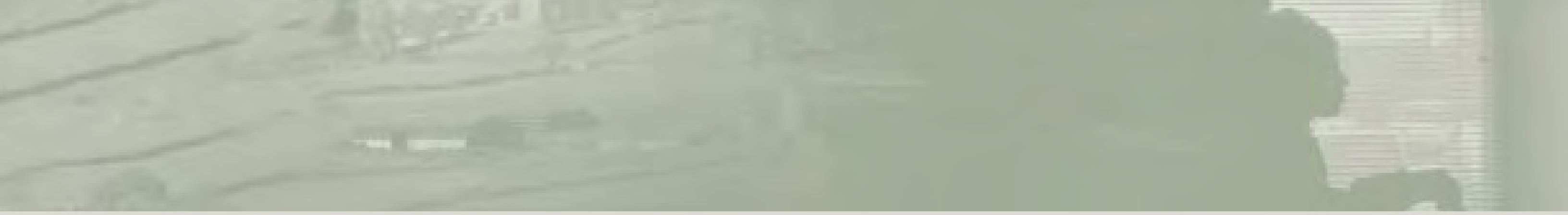
[24] Lynn, J, Schuster, JL, Kabcenell, A. *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians.* New York: Oxford University Press, 2000.



The Meaning of Quality to the Consumer

From the patient and family's standpoint, it would be reassuring to count on the same minimum level of services from provider to provider and from state to state. Differences in the provision of inpatient care, residential care, continuous care, palliative chemotherapy and radiation, and palliative care consultations make this goal of consistency difficult to achieve.

It is clear that quality is on the national agenda and occupying an increasingly central role for consumers and for payers, including the Centers for Medicare and Medicaid Services. Quality initiatives must address the degree to which care is:

(1) effective
(2) patient-centered
(3) safe
(4) efficient
(5) timely
(6) equitable

Payers are currently researching methodologies for determining level of reimbursement to providers based on performance (i.e., quality).

All providers are being encouraged to start with reasonably scaled efforts to respond to these mandates. Results of quality monitors can facilitate staff education and promote progress. Board members should routinely review quality data as part of their governance responsibilities.

Identifying Outcomes in End-of-Life Care

Measures for evaluating the efficacy of end-of-life care are different from measures for health care interventions where benefits of treatment are commonly expressed in terms of functional improvement, such as return to work or increased ability to communicate. End-of-life care addresses a phase of life rather than an isolated episode of illness or treatment. Consequently, end-of-life assessment processes frequently seek to quantify personal experience regardless of diagnosis. Of necessity, such measures are more subjective, but no less meaningful, than lab values. It is important to identify appropriate and non-intrusive elements of care to quantify, while at the same time avoiding the notion that "dying well" is simply a sum of data points.[25]

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[25] *Report of the Outcomes Forum*. National Hospice and Palliative Care Organization, Alexandria, VA: www.nhpco.org.

One major initiative to address these challenges is the Outcomes Forum, a joint effort of NHPCO and the National Hospice Work Group, San Diego, CA. The Outcomes Forum was largely based on:

(1) the conceptual framework for outcome domains identified in a two-year consensus-building process involving over 500 hospice clinicians and managers;

(2) an extensive literature review; and

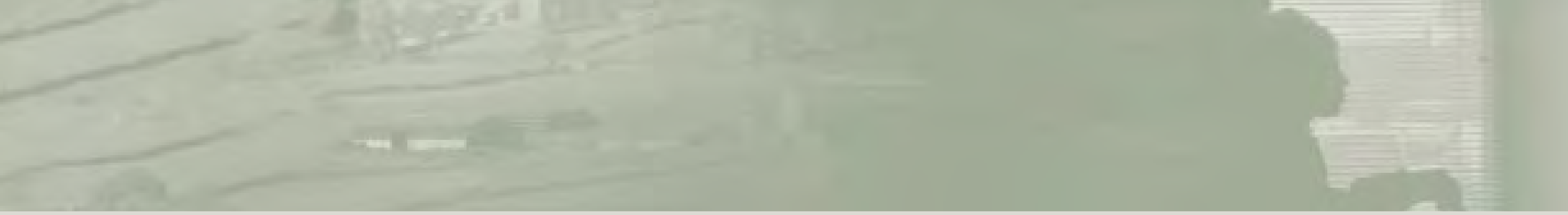
(3) review of the medical records systems of 22 hospice programs.

The four domains described below are the cornerstones of the landmark 1997 NHPCO document, *A Pathway for Patients and Families Facing Terminal Illness*. The Outcomes Forum, in particular, challenged itself to develop memorable language and hardy measures that would help establish quality expectations among consumers as well as relate to the interventions of health care professionals and needs of payers.

Outcome Domains

Safe Dying: The patient will die with family caregivers feeling confident that they are competent to provide care safely at home. The caregiver confidence measure was developed based on research on mothers and their pre-term infants and their self-confidence associated with providing care. This measure of caregiver confidence is also part of the N*HPCO Family Evaluation of Hospice Care*, a perception-of-care survey for the family survivors of hospice patients. (More information on the *Family Evaluation of Hospice Care* survey process is available on the NHPCO website, *www.nhpco.org*, in the Statistics and Research section.)

Comfortable Dying: The patient will die free of distressing symptoms in an environment that does not aggravate or hasten dying. Barriers to comfortable dying can include physical distress as well as emotional despair, depression and spiritual distress. The measure for this domain, pain, was chosen because pain is a widely recognized and measurable issue in symptom management and a widespread fear by consumers. Pain is measured on admission and then 48 hours after admission. The pain measure, using a yes/no answer to the question, "Was your pain brought to a comfortable level within 72 hours of your admission to the hospice program?" has been tested and validated and is being used by many hospices as a quality



measure. (More information on the pain measure and the procedure for using it can be found on the NHPCO website, *www.nhpco.org*, in the Statistics and Research section.)

Self-Determined Life Closure: Anticipating death, mentally competent patients will have full autonomy to make decisions about how the remainder of their life is spent, within the allowances of law. This domain identifies two measures regarding patients' preference — hospitalization and resuscitation as their condition worsened or death occurred. The questions are asked of patients or their legal representatives, with their wishes on admission and any changes in preferences recorded. The questions are: "Do you want to avoid hospitalization if your condition worsens?" and "Do you want cardiopulmonary resuscitation if your heart and lungs stop working?" (More information on the measure and the procedure for using it can be found on the NHPCO website, *www.nhpco.org*, in the Statistics and Research section, End Result Outcome Measures.)

Effective Grieving: The expression of grief will eventually support individuals' ability to adjust to their environment without the deceased and regain the ability to invest in other activities and relationships. This domain identifies two questions to be asked at different times during the grieving process, one two months after the patient's death and the other 13 months after the death. The two-month question is: "Did hospice staff provide effective emotional support for you in preparing for the death of your loved one?" The 13-month question is: "Did hospice staff provide effective support for you in coping with changes in your life since the death of your loved one?" The effective grieving measure is undergoing review and a new bereavement measure should be available on the NHPCO website in 2006. (For more information on this measure, see the NHPCO website at *www.nhpco.org*, in the Statistics and Research section, End Result Outcome Measures.)

Quality Initiatives in the Real World

Examples of rural hospices and palliative care providers that have made a more formal commitment to quality include:

- High Peaks Hospice in Saranac Lakes, NY, which uses surveys and questionnaires to assess patient satisfaction. The agency self-assesses its program annually for each office using NHPCO's *Standards of Practice for Hospice Programs* and related self-assessment tools. Each office uses separate measures as part of its performance improvement efforts. Current measures are tracking pain management and the length of time between referral calls and informational visits to patients, while past measures have used patients' agitation and anxiety levels as a quality monitor.
- VistaCare nationally has a strong quality assurance program, with its local offices' performance regularly monitored and trended against high standards. In VistaCare's rural Hobbs, NM, office, there is an annual quality calendar with monthly reports on designated issues, monthly meetings focused on the local quality assurance data, and reports back to the corporate office. The outcomes of these efforts are used to generate user-friendly quality information.
- The collaborative palliative care initiative now under development in Littleton, NH, is being initiated with an explicit commitment to quality measurement and continuous improvement. Draft standards of palliative care have been prepared for physicians, pharmacists, hospice and home care. ***(See Attachments in Appendix G for samples.)*** In addition, the palliative care team has developed a written procedure for the intake nurse to follow when conducting an initial assessment. With input from the hospital, the palliative care team has created an initial clinical assessment documentation tool, a mechanism for charting active patient needs/problems, specified end-of-life care goals, and possible palliative care consultation team members (by function) whose services may be included when consultation and/or referral is requested. It is expected that these policies and procedures will be refined once the quality improvement initiatives are instituted.

Providing Hospice and Palliative Care in Rural and Frontier Areas

Chapter 13:

Delivery of Hospice and Palliative Care in Rural Areas: A Policy Discussion

Chapter 13: Delivery of Hospice and Palliative Care in Rural Areas: A Policy Discussion

Philosophically, all Americans, no matter where they live, deserve to have access to quality end-of-life care services. Many providers of hospice and palliative care in rural areas are doing a remarkable job of meeting their communities' care needs. Providing ready access to comprehensive care stretches providers and demands ingenuity and creativity. This paper will discuss the policy issues that shape and constrain the provision of hospice and palliative care in rural areas and the policy challenges faced by rural providers in their efforts to meet these goals.

Demographics of Rural/Frontier Areas

While the economies of some rural communities have limited employment and/or wage and salary opportunities, several of the sites visited are populated by professionals who have made a choice to live in the area based on perceived quality of life. Many rural and frontier areas reflect an aging population, although older citizens often constitute a rich source of professional experience, board service and/or program volunteers. It is also true that former images of America's rural communities as ethnically homogenous no longer hold true in many locales as changing demographics and an influx of new residents redefine the cultural mix.

Financial Concerns of Providers in Rural Areas

Serving a rural area means longer driving times, bad roads, weather-related challenges, reduced staff efficiency, limited economies of scale, and thus higher unit costs. That reality affects hospices and palliative care providers in several ways:

1. Many rural nurses have the option of commuting to an urban or semi-urban hospital where the salaries are high, so some rural providers have to compete with their urban neighbors' salary and benefit levels.
2. The cost of operating a car, including gasoline and servicing, is now higher than the Federal mileage reimbursement rate. Even if the provider is able to pay its staff a higher mileage rate to cover increased gas costs, the additional amount would create an income tax liability for the employee.
3. Rural providers have less ability to invest in information systems that could make patient record keeping and electronic billing more effective and efficient.

Grant funding and collaboration and support from other providers in the area are possible solutions to these problems. It should be recognized, however, that grant funding is a temporary solution and it calls for specialized writing skills that may or may not be readily available in these settings. Similarly, partnerships have many fine attributes but are usually built slowly, over time, and therefore may not be a ready solution to the press of current demands.

> ***Hospice Payments:*** Medicare reimbursement rates for hospice services provided in rural areas usually fall below the rates paid to more urban areas. This is so despite the cost factors identified above.

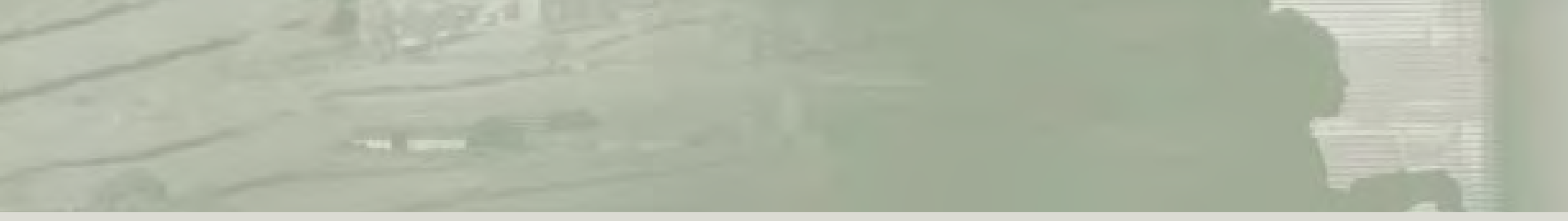
Difficult Medicare Hospice Requirements

Medicare hospice certification requires professional core team members who possess specified educational credentials and are sufficient in number to provide the required four levels of care *(see Appendix C)*. Medicare requires that the hospice social worker, a mandated member of the interdisciplinary team, have a BSW degree from a school accredited by the Council on Social Work Education. Many hospices in rural areas have expressed frustration and concern that there is no qualified social worker to be found in their service area. The regulations allow for no exceptions to this requirement and, as a result, hospices have gone to great lengths to meet it. Special scholarships and tuition repayment service incentives would be most helpful in redressing this issue, as would careful consideration of ways to provide effective distance oversight of counseling services.

Medicare-certified hospices are also required to name a physician as the medical director and to have that medical director serve on the interdisciplinary team. In many rural areas, physicians are in short supply. Finding a physician who has some understanding of hospice and palliative symptom management, as well as time to contribute, can be difficult.

One level of care required from Medicare-certified hospices is continuous care — which is provided to the patient and family during periods of medical crisis wherever the patient is living, thus avoiding hospitalization. The regulations require that the staffing of continuous care be at least 50 percent nursing. Finding staff to provide extra nursing services for patients in 4-to-8-hour shifts is often difficult with the limited number of nurses available in some rural areas. Definition and encouragement of creative partnerships with other area providers might help meet the demand. Effective use of on-call staff, if available, is another possible approach.

Hospices are also required to have contracts for inpatient care with community hospitals, or with the hospitals where their patients receive inpatient services. This requirement is sometimes met through a contractual relationship with a hospital in a distant urban area. Unfortunately, there is a structural disincentive that has the effect of discouraging urban hospitals from contracting with rural hospices: the Medicare Hospice



Benefit covers a day of hospice inpatient care at a specified per-diem rate, but the rate received by urban hospices is much higher than the rate received by their rural counterparts. A payment structure enabling the hospice to pay the hospital at the prevailing urban inpatient hospice rate would help offset this problem.

If there is only one hospital in the community and it says it doesn't have any available beds, is constrained by the Critical Access Hospital rules *(see Appendix B)*, or is otherwise unwilling to offer the hospice a bed contract, the hospice is in jeopardy of being out of compliance with the Medicare requirement to offer all four levels of care. It would be most helpful if there were a policy addressing this particular consideration, providing both the hospital and the hospice with reasonable provisions for meeting care needs.

Palliative Care Services

Funding for palliative care services is readily available in the form of payment for professional services. However, the demand for physicians, advanced practice nurses and registered nurses trained in hospice and palliative care far exceeds the supply. Further, as practitioners of a relatively new specialty, palliative care providers are in the position of having to justify and demonstrate their skills and abilities as specialists and as consulting colleagues. The rapid growth of palliative care programs in inpatient settings is referenced in this paper. As a result of this growth, hospital partnerships will be particularly important as this new entity comes of age.

In addition, many hospice providers are initiating community-based palliative care programs to extend their service reach further into populations of need. Grants are needed to support educational opportunities for practicing physicians and nurses. Technological linkages to academic medical centers with palliative care training programs would provide inexpensive opportunities for on-site consultation and training. The continuing development and dissemination of documentation tools and clinical protocols suitable for rural and frontier providers is also a priority.

Other Medicare Constraints

In other parts of the Medicare program, provider regulations work at cross purposes with the provision of hospice and palliative care in rural areas.

For example, 1915(c) waiver programs created by states to keep patients in the least restrictive setting and in the community often force the patient to choose between the waiver program services, typically home health aide services, and hospice care. This dilemma is not unique to hospices in rural areas, but is an access barrier found in many parts of the country. A careful review of the unintended consequences of this policy might yield recommendations about how to provide patients with the services they deserve in a cost-effective manner.

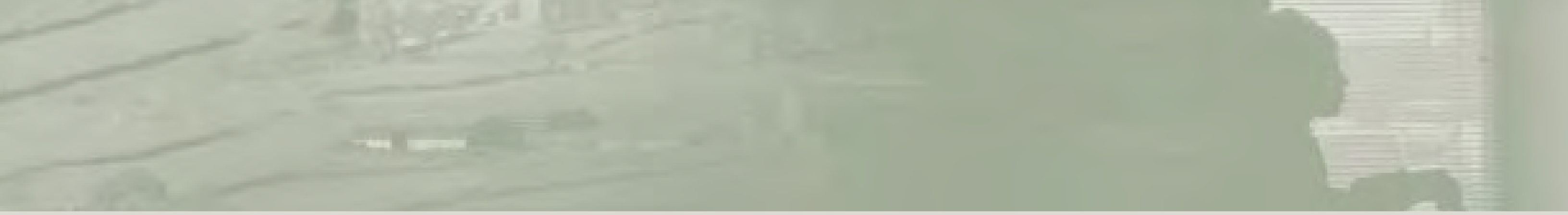
Some other Medicaid waiver programs have been supportive of hospice involvement, but eligibility for relevant services is now tighter. In some cases, all available resources are committed. The end result of this circumstance can be a waiting list for services and/or limited or no availability for terminally ill patients. Since the intent of these waiver programs is to enable access to needed services, a review of the actual consequences is needed before solutions can be designed.

The Program of All-Inclusive Care for the Elderly (PACE), a Federal comprehensive long-term care model based on San Francisco's pioneering On Lok Senior Services, is of great interest to providers in all geographical areas, given the aging population. The development of PACE programs has been primarily concentrated in more urban areas, but renewed interest and authorization for more PACE sites, including rural demonstration sites, undoubtedly will make this program one that rural providers will want to pursue. NRHA also has a rural technical assistance project involving PACE that could be helpful to rural providers. However, if a patient enrolls in a PACE program, it is often difficult for that individual to access his or her Medicare hospice benefits. Demonstration projects are needed to test the potential of partnerships between PACE programs and hospices and palliative care providers.

Support for Extending the Continuum of Health Care

The rural providers profiled in this toolkit have worked innovatively and tirelessly to find ways to support and extend the full continuum of care for patients and families confronting life-threatening illnesses. Issues that have been identified for rural providers in extending the care continuum include:

- Assuring access to hospice- and palliative care-trained physicians;
- Assuring access to qualified social workers;
- Creating access to specialized medical expertise and consultation, including such specialties as oncology, neurology or hematology and the medical specialty of palliative care;
- Finding funds to support the initiation of telemedicine services for patient care, so that patients in remote areas can access medical consultation without leaving home;
- Overcoming financial barriers to implementing palliative care programs in partnership with hospitals;



- Collaboration among all parts of the health care system in the community — so that the “holes” in the health care system are plugged; and
- Provision of pediatric care. Many rural hospices provide little or no pediatric care. In one example, there are no pediatricians in the community, so the hospice says it simply can’t admit these patients. Definition of service opportunities encouraging recent graduates to provide services in rural and frontier areas as part of loan-forgiveness programs could be helpful. In addition, technological linkages to academic medical centers might enable local providers to obtain the supervision they need to offer a more comprehensive range of services to area children.

Rural providers that contributed to this toolkit are also interested in increasing the availability of palliative care education for physicians and other health care professionals, which could be encouraged through mechanisms outlined in the paragraph above.

Policy Issues to Consider

The policy issues discussed in this chapter deserve additional advocacy. As site visits, surveys and telephone interviews have been conducted, the priorities for addressing these policy issues have become clear. Those priorities include:

1. *Critical Access Hospitals (CAHs)*. The statutory requirements for CAHs do not allow an exemption for hospice patients in the hospital for a General Inpatient day of care under the Medicare Hospice Benefit. The specific issues that have been raised by hospice providers have been analyzed by CAH consultants and CMS staff, and all agree that a statutory change will be required for a “fix” to this complex problem. The National Rural Health Association (NRHA) and the National Hospice and Palliative Care Organization (NHPCO) have both placed this issue on their legislative agendas for the coming year. (***See Appendix B*** for more information on this issue.)
2. *Clarification of the 1915(c) waiver programs*. Such clarification could allow home health aide services for hospice patients under Medicare or Medicaid at the same time as the waiver services. In some states, hospice services have been determined to be duplicative of waiver services, although the hospice does not provide attendant care or caregiver services under Medicare and Medicaid. The clarification is a regulatory one, and would need to come from CMS.

3. *Funding for medical education*. Funding possibilities for medical education could be explored specifically for palliative care education in rural areas. This is a longer term possibility, with Congressional budget implications. Both NHPCO and NRHA should explore this option.

4. *Telemedicine/Telehospice*. Funding possibilities for telemedicine for hospice and palliative care in rural areas should also be explored. Funding could be available from diverse Federal agencies; research is needed to identify possible funding sources and their requirements for rural areas.

5. *Financing*. The challenges associated with providing care in rural and frontier areas have been well-documented. As a result, special financing models and in some cases waivers have been designed to enable hospitals, clinics, home health agencies and PACE programs to offer care in these settings. A study is needed to assess the separate and collective impact of these initiatives on access to hospice and palliative care services. The outcomes of this study could then be incorporated in health policy recommendations.

NRHA and NHPCO should seek additional partners at the state and Federal levels to explore solutions to these policy issues. Patients and families will benefit from the advocacy required to make access to hospice and palliative care a reality for all.

CENTER TO ADVANCE PALLIATIVE CARE
National Hospice and Palliative Care Organization
NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Vignettes

Vignettes

Vignette 1: Hospice of the Red River Valley, Fargo, ND

Rural Hub Hospice Model

In 2001, in response to a foundation grant for improving organizational capacity, Hospice of the Red River Valley (HRRV) engaged management consultants from the Summit Business Group to review its current operations and organizational challenges. “They told us, ‘The answer to every one of your dilemmas is to grow your census,’” recalls Executive Director Susan Fuglie. “We had been operating on a number of self-limiting assumptions, which we have since been working on overcoming.”

After hiring a nearly full-time medical director and focusing on improving customer service and expanding access to care, HRRV has made great strides in growing its census, particularly in its four regional (or satellite) offices. “There came a point for this organization when we realized we weren’t a small, mom-and-pop operation any more. There had to be a paradigm shift to seeing ourselves more as a business,” Fuglie says. “There has also been a ripple effect from growing the census; it begets more growth. And boy is it fun.”

While HRRV’s home base of metropolitan Fargo-Moorhead has a population of 150,000 (surrounded by agricultural areas of the Red River Valley of the North), its four regional offices — three in North Dakota, one in Minnesota and all about an hour’s drive from Fargo — are in towns of less than 10,000 people. Each office serves a radius of up to 60 miles, and the current service area includes all, or portions of, 19 counties. In August 2004, daily census had reached 200, up from an average of 100 in 2003. Slightly more than half of the census is served from the Fargo hub office, but growth has been more dramatic in the regional offices.

The goal in operating the regional offices is to keep as many clerical and administrative functions as possible based in the Fargo office so that each regional office can focus on patient care and community service. Each office has a nurse program manager, based in the local community, who focuses on operations and census-building rather than carrying a caseload. Typically, the program manager is a lifelong resident of the community, not a transfer from the Fargo office. “We try to give them as much authority as feasible,” balanced against the need for standardization of services across sites, Fuglie says. “Every community is distinct. How do you find a balance between unique local elements and what needs to be consistent in how we run our program?”

Other team positions depend on actual census and sometimes curious blends of positions are required to balance the office as census grows. A social worker, bereavement coordinator, volunteer coordinator or other position may also be shared between regional offices. Each site has a part-time chaplain, a volunteer medical director, part-time personal care aides and an office nurse, typically an LPN. “We have paid premiums and put people into hotels to take care of on-call,” Fuglie says. In one office there was insufficient demand for a full-time nurse, so it became necessary to schedule on-call coverage during the day, as well.

When caseloads lag, she adds, it is the program manager’s responsibility to step up marketing efforts to nursing homes and physicians and the community. “The answer is always to grow the census. Don’t just wait for calls to come in.” Although rural care generally is more costly to provide, different offices will carry each other financially at different times. It isn’t always the Fargo office subsidizing the others. “Bottom line: we’re all in this together.”

Vignette 2: Hospice of the Wood River Valley, Ketchum, ID

Volunteer Hospice Model

Hospice of the Wood River Valley (HWRV) is an exemplary illustration of a rural hospice program that has become a primary source of end-of-life care for its community without participating in Medicare reimbursement. But its atypical resources, community and setting — the Sun Valley ski resort, a major tourist destination — may bestow advantages that would make it hard to replicate the program's success in other rural areas. Two factors, in particular, help to explain its success.

One is the relative affluence and disposable income of the region's population, which provides approximately $250,000 per year in charitable support to HWRV. The other critical factor is the credibility, leadership and dedication of Executive Director Carolyn Nystrom, who has held that position since 1990 and piloted the hospice's growth and involvement into all aspects of end-of-life care for its community.

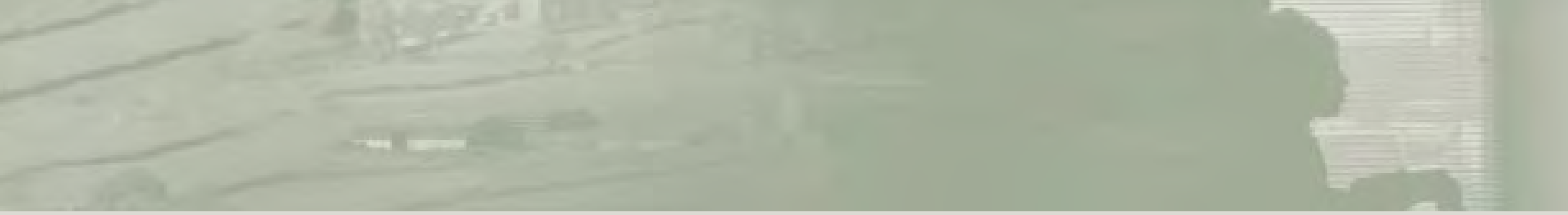
Nystrom, a nurse, brought to the position prior experience running a hospice in another state. When she took over the struggling hospice, she reduced her own salary to part-time status until funding could be established on a stronger footing. She first focused on conducting a broad needs assessment across many levels of the community while continuing to provide services. In her second year, she concentrated on fund development and restructuring the Board of Directors. Her commitment to economy and careful stewardship of the agency's donated resources is reflected in current, somewhat spartan staffing, which also includes an office manager and two not quite full-time RN case managers for a hospice ADC of 22, plus extensive community and bereavement commitments.

Nystrom is tireless in her job at age 67. Still concerned about shepherding precious community resources, she wears multiple hats and even makes soup for various meetings at the office. How the program will respond to her inevitable retirement remains to be seen, although the Board of Directors has developed guidelines for how to go about replacing her ***(see Attachments on p. 146-148)***. "In the Event of an Unexpected Vacancy of the Executive Director" is a protocol outlining in detail who would fill various functions to keep the hospice running without interruption in service, while the search for a new executive is laid out in a 13-step process.13

The hospice's primary service area, Blaine County, has a population of 19,000 spread across 2,466 square miles, although most of that population is concentrated in and around the Sun Valley towns of Ketchum, Hailey and Bellevue. The rest of the county is comprised of isolated ranches, mountainous terrain and national forests. Blaine County meets the Frontier Health Center's definitions of "frontier," while two adjacent counties that receive limited (i.e., telephonic) support from HWRV are even more sparsely settled and isolated.

Blaine County has one highway in and out of the valley, with mountains on three sides; there are two weekly newspapers and no home-delivered mail. Cell phone service is spotty. There is only one hospital, nursing home, assisted living facility, home health agency and funeral home — which tend to encourage cooperation among providers. Most specialty medical care is provided in Boise, 2-1/2 hours away by car.

The hospice has not sought Medicare certification or reimbursement and has no plans to do so, avoiding



Medicare's regulations and instead drawing upon the community's support to cover its payroll and other operational costs. "Medicare would have limited our discretion in taking patients," said Board President Leslie Andrus, who is also a hospice volunteer. "If you don't need Medicare funds, why accept the restrictions?"

Nystrom is determined that HWRV not be a "backward" hospice even though it serves a rural community. "A lot of people feel rural is less than the best. That's clearly not true here. I have a real commitment to providing excellence in end-of-life care and bereavement services," she said. All of HWRV's services are included in its 24-hour on-call coverage. The nurses, who meet every Monday morning, share the caseload, call and bereavement, and are familiar with all of the patients, so that any of them can respond to needs that arise during the day or after hours.

The additional services provided by HWRV — whether community education, grief response in the schools, collaboration with the community's first responders (including police, EMS and Search and Rescue) and a supportive presence for families of patients in the hospital's emergency room — reflect its commitment to meeting the community's needs. Counting all of those interventions, Nystrom estimates that HWRV had some involvement with 92 percent of all those who died in the county in 2003, either through terminal illnesses, unexpected deaths, or bereavement support.

Vignette 3: Sioux Valley Hospital/University of South Dakota Medical Center Adult Palliative Care Consultation Team/Sioux Valley Hospice, Sioux Falls, SD

Inpatient Palliative Care Service and Affiliated Health System-Based Hospice

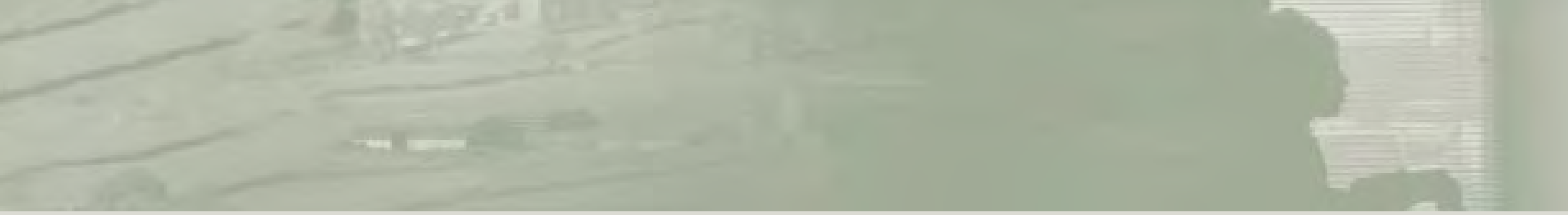
In Sioux Falls, SD, related hospice and palliative care programs are designed to extend end-of-life services across expansive, sparsely settled rural areas within the limitations of existing resources and reimbursement. Sioux Valley Hospice and the Adult Palliative Care Consultation Team, both affiliated with Sioux Valley Hospital/University of South Dakota Medical Center, share the same medical director, Dr. LuAnn Eidsness. Some of the staff members have worked for both programs; their synergy is described as primarily mutual awareness, streamlined communication and "just lived experience."

The medical center has 476 beds, making it the state's largest health facility, and is affiliated with its only medical school. The center is the hub of a regional health partnership of 140 facilities. It supports end-of-life program development and education in various ways, such as founding and sponsoring the South Dakota Partnership for End-of-Life Care, a statewide coalition with an educational focus. Eidsness and other palliative care team members field phone calls from health professionals around the state requesting consultation and advice. The program is exploring funding opportunities that would make it possible to formalize and strengthen long-distance support to rural health professionals — perhaps even sending staff on the road to provide consultation and education.

The palliative care service, launched in 2000, consulted on 263 patients in 2003 and more than 350 in the first eight months of 2004. Eidsness, who also chairs the medical center's Department of Internal Medicine, is available on-call for palliative care and plays an active role in clinical oversight for the hospice and palliative care programs as well as in ethics activities. The team has targeted specific groups of patients, such as those in the lung cancer clinic, receiving dialysis or with pulmonary disease. Expanding relationships with ICUs and hospitalists are the next targets.

The 10-member palliative care team includes a physician, a clinical nurse specialist, three social workers, three chaplains, a dietician and a pharmacist. At the present time, only the physician's consulting services are billed. Other members of the team add time to their other job responsibilities to conduct palliative care consultations. The team also provides limited coverage for an outpatient palliative care clinic and the medical director has made two home palliative care visits in the immediate Sioux Falls area for hospitalized patients released to their homes.

Although there is significant potential for the delivery of services outside the hospital setting, the palliative care program currently is primarily inpatient in focus, providing multi-disciplinary consultations on referral from physicians at the medical center. Team members also participate in connecting discharged patients with services in their home communities in South Dakota and the neighboring states of Minnesota, Iowa and Nebraska. Some of those patients, however, return to locales without organized home health care or hospice services — particularly in Northwestern South Dakota. For those patients, the palliative care team tries to provide a lifeline of telephonic follow-up — a partial and imperfect solution to the needs of patients with life-threatening conditions who otherwise might receive no palliative support at all.



The hospital chaplains try to make one follow-up call to clergy in local communities for palliative care patients who are headed home. Three hospital social workers share palliative care responsibilities and have managed to carve out several hours a week to make follow-up phone calls to patients discharged to communities without adequate home-based services. A total caseload of 10 to 12 such discharged patients is being followed at any given time by the social workers in this very part-time role.

Part of the social worker's job is to develop a virtual rolodex of existing services and resources in each community, using the phone book and calling local churches and service groups. Sometimes existing resources are not well-coordinated, so the social worker makes every effort to contact the patient's attending physician and to facilitate integration of needed services, to the extent that these goals are feasible by long-distance calls.

The affiliated **Sioux Valley Hospice** (SVH) was founded in 1987, becoming the first Medicare-certified hospice in the state. It has eight offices that together cover an area approximately 360 miles wide by 190 miles deep, extending across Eastern South Dakota, Southwestern Minnesota and Northwestern Iowa, with a combined census of 80 hospice patients. The program is also affiliated with the health system's home health agency and durable medical equipment companies. In most areas where SVH has a satellite office today, the Sioux Valley health system had been approached by local groups and asked to assume responsibility for a struggling volunteer hospice program.

Each hospice site has a program manager based in its community. Arrangements for staffing the rest of the team and covering on-call require ingenuity, flexibility, the use of part-time staff and, often, shared staffing and resources with other offices. Social workers handle bereavement responsibilities, including grief and caregiver support groups. Each site also has a volunteer medical director, access to a clergy volunteer and a group of patient care volunteers. The program managers convene monthly at the Sioux Falls office, which also houses centralized administrative functions, while SVH coordinator Lois Schuller visits each site office at least quarterly. SVH also operates three four-bed residential hospice cottages.

The challenges of providing palliative and hospice care in rural areas are being explored in somewhat different ways by **Hospice of Siouxland**, a community-based hospice across the state line in Sioux City, IA. Hospice of the Siouxland serves a somewhat smaller rural area with two branch offices, 25 and 38 miles away from its hub, and a total hospice census of 195. The hospice recently completed a $1 million capital campaign to launch a new product line, a home-based palliative care consultation service that now carries a census of 83. This service is staffed with a physician plus nursing, social work and chaplain staff and a separate volunteer component, some of which is affiliated with a Faith in Action volunteer program.

Palliative care patients and private insurance companies are billed for the service, with a sliding scale, although the program does not yet bill Medicare Part B for its physician consultations. The palliative care program works collaboratively with two local home health agencies, working to fill service gaps while trying to avoid duplicating the services of others.

Vignette 4: VistaCare Hospice, Hobbs, NM

Multi-State Hospice/Frontier Hospice Model

It would be difficult to find a site more representative of a frontier location than Hobbs, NM. The VistaCare hospice program based in Hobbs covers a service area encompassing more than 2,000 square miles and the most recent U.S. Census survey found only 4 people per square mile. Including those who live in outlying areas, the total regional population is approximately 50,000. The average daily census of the Hobbs hospice program is 130 to 140, approximately 40 of whom receive their care in nursing homes. According to those who live in this area of New Mexico, frontier can be defined as a place that has "more dirt than people."

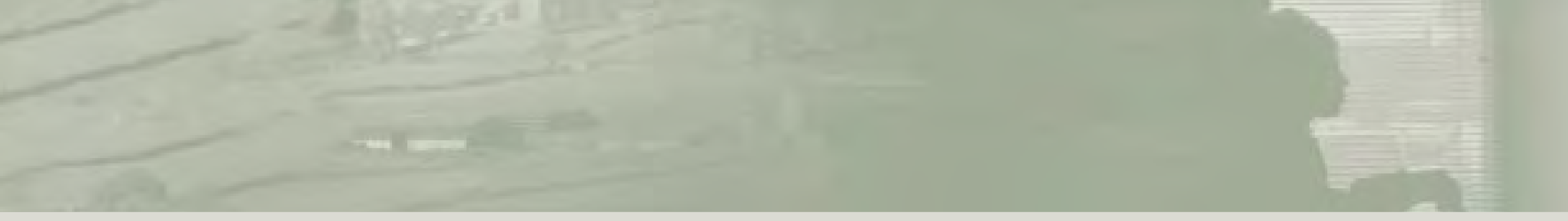
Creating and sustaining communications connections in the Hobbs territory demands innovative problem-solving. Because cell phone coverage is spotty, patient visit schedules are prepared and staff is encouraged to stay close to targeted time frames. This approach usually enables contact as needed via POTS (plain old telephone service). An additional reason for the visit schedule is concern for the personal safety of staff. Knowing where staff members are meant to be and when they are meant to be there provides the agency with detail on location that could be important in the event of an automotive breakdown or accident.

Located in proximity to the Mexican border, the Hobbs VistaCare program serves many Hispanics. In addition, there is a relatively large population of African-Americans. Approximately half of the total staff of 65 self-identify as minorities. This scenario makes it possible for the program to address the needs of its Spanish-speaking patients and families and to bridge socio-economic barriers. However, there are still too few bi-lingual field nurses and nurses aides in training. Recruiting and retaining staff with these language capabilities is difficult. The AT&T language line is a helpful resource. (More information on the AT&T language line can be found at *www.languageline.com*. It has options for communicating in 150 languages and is available 24 hours a day, 7 days a week.)

Consistent with findings in other rural and frontier areas, access to hospital beds is a growing problem. Three of the hospitals in the area are Critical Access Hospitals and have not agreed to partner with the hospice; two more are seeking this designation and have already voiced concerns that it would be more financially difficult for them to contract for hospice services if they receive the CAH designation. Fortunately, the VistaCare program enjoys a strong positive relationship with the one hospital in Hobbs.

The region is served by a very limited number of physicians; for example, there are no oncologists. As a consequence, many patients travel to the nearest major city, Lubbock, TX, seeking specialty and/or acute care. This lack of oncology services in Hobbs changes the diagnostic mix of patients. For example, cancer patients account for 20 percent of the Hobbs diagnostic mix while the remaining 80 percent have non-cancer diagnoses. (Nationally, cancer patients represent half of hospices' caseloads.)

The Hobbs program offers educational outreach to physicians and the community so they know there is a VistaCare program in Lubbock to enable continuity of hospice services. Further, there is a VistaCare liaison nurse manager in Lubbock who enables a smooth transition for patients known to be in the hospital system. However,



unidentified patients often return to Hobbs with little or no information on their prior course of treatment or recommended plan of care.

The VistaCare program relies on many volunteers to extend services and enhance community connections. Unfortunately, finding new volunteers is becoming increasingly difficult. The current pool is largely senior citizens, many of whom, while generous with their time, have health issues of their own and/or limited availability due to concerns about driving at night or in inclement weather. Jessica Hood, Executive Director of the Hobbs VistaCare program, reports that it is easier to find volunteers to assist with administrative tasks in the office and more challenging to fill the necessary number of clinical volunteer hours. Interestingly, some of the more recently recruited volunteers include a counselor, two notaries and some pastors, who can offer professional services.

A distinguishing feature of this program is the strong quality assurance initiative sponsored by the VistaCare Corporation, which as of December 31, 2003, operated 40 hospice programs serving a combined census of 5,140 patients in 14 states. The quality assurance program is based on an annual focused agenda with specified reporting requirements. The Hobbs quality assurance team meets on a monthly basis and submits local data to a corporate team for analysis. The resulting information is used to improve performance. The Hobbs site is benchmarked against other VistaCare sites, each of which is connected to a web-based technology infrastructure enabling secure, rapid and remote information access. While telehospice services are not yet available, corporate leaders see an exciting future role for this technology.

Despite the challenges of its location, the VistaCare program in Hobbs could be considered a poster child for hospice success both in terms of its diagnostic mix and its length of stay, which averages 217 days (114 days median). Based on NHPCO indicators, market penetration is at 120 percent, suggesting effective outreach and a positive public perception about program services.

In addition, a special program, Care Connect, is designed for patients who are not eligible for the hospice benefit. For this program, VistaCare employs a nurse who calls patients on a regular basis to share educational information about health-related issues and offer suggestions about when to make physician contact. Area physicians particularly appreciate the linkages created with community agencies to help patients get the services and supplies to which they are entitled. While Care Connect enables the Hobbs program to develop a relationship with patients and families early in the course of the disease, staff recognizes the need to explore additional outreach options and sees community-based palliative care offered by nurse practitioners as a possible mechanism for future growth.

Jessica Hood views the relationship of this hospice with its community as the key to its success:

> *The community is very supportive of the end-of-life services we offer. We have worked hard over many years to gain this level of trust. In a rural market, credibility is based on personal integrity and performance. While our corporate structure is a real strength, it is the personal connection with the community that secures our position. Boundaries and confidentiality can be concerns but the benefit of personal connections and support are essential to our work.*

Vignette 5: Hospice Services, Inc, Phillipsburg, KS

Small, Independent Hospice with Informal Palliative Care Services

Hospice Services, Inc. serves northwestern and parts of north central Kansas, an area of approximately 12,600 square miles with a population of less than 60,000. Sandy Kuhlman, Executive Director of Hospice Services, Inc., has been with the program since 1982. Her philosophy and message are clear — to both succeed as a hospice organization and continue providing quality end-of-life care to those in the community, the organizational mindset must extend beyond the organization. In Kuhlman's words, "Hospice can be the main focus… but it cannot be the only focus; we must focus on the sustainability of the entire community."

Hospice Services, Inc. has an average daily census of 17. The program provides Medicare hospice services and does not have any formal bridge programs at this time. However, it does provide palliative care informally and in partnership with other health care providers such as area hospitals and home health agencies. Physicians and health facility staff may contact hospice staff with questions about pain control and symptom management. At least two nursing facilities contact the hospice to determine if someone might be an appropriate hospice referral. Hospice Services, Inc. leverages its relationships in the community to provide education about palliative and hospice care both formally and informally. Several hospitals have offered the hospice space within their facilities for its staff to complete documentation, make phone calls and store supplies and equipment.

Hospice Services, Inc. has a staff of fifteen including a part-time medical director, seven nurses, three social workers (two BSWs and one LCMSW), and one director of volunteers and three office staff, including the director, who is also a nurse. The medical director is a member of the Academy of Hospice and Palliative Care Physicians and is pursuing certification in hospice and palliative care.

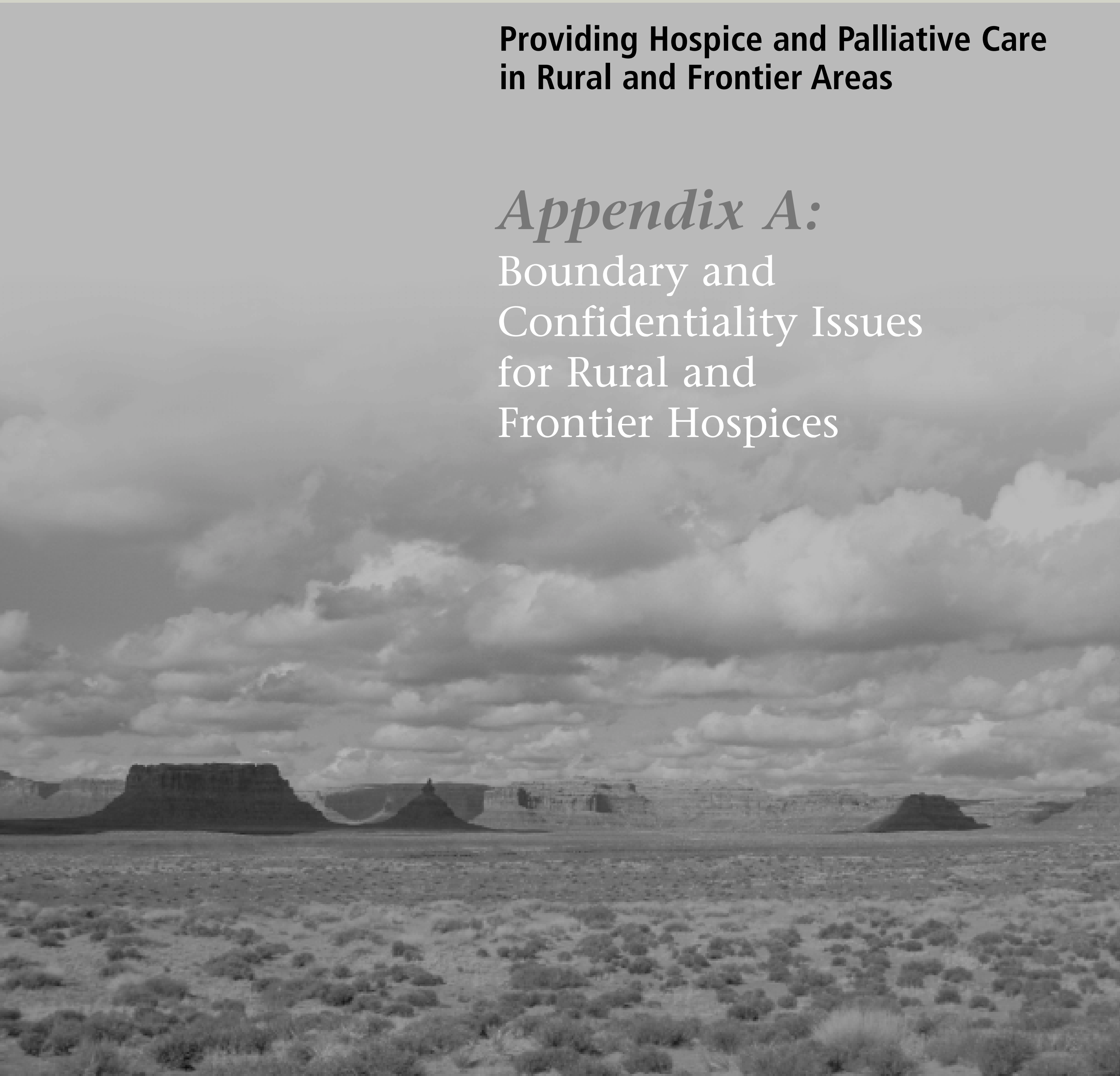
Building, strengthening, and maintaining relationships in the community are important parts of the work of Hospice Services, Inc.; both with residents of the community and with any group or organization that can help achieve desired outcomes. Partnerships have been established with hospitals, home health agencies, long-term care facilities and rural health clinics. These reciprocal relationships allow Hospice Services, Inc., to extend the range of options patients and families enjoy, enabling them to remain at home or in facilities within their community, while improving access and quality of services in the community. Kuhlman personalizes this effort by creating a "cheat sheet" to track the names of staff at community organizations and items discussed during each visit.

Charitable dollars constitute 30 to 40 percent of the organization's revenue. The reason for success in raising charitable dollars, Kuhlman believes, is a combination of the visibility and perceived quality of Hospice Services, Inc., initiatives. Philanthropic dollars support staff education; each part-time or full-time staff member is eligible for an annual continuing education subsidy including registration, hotel and mileage. Charitable support also allows the hospice to care for those without health insurance and to assist with covering costs of care for families with limited means. The good stewardship of donated dollars is well-known at the local level and in turn increases giving.

Networking with many different community organizations has contributed to the growth and sustainability of Hospice Services, Inc. Peer relationships have been established with hospices serving other counties, allowing networking opportunities for Hospice Services, Inc. The significance of building and strengthening relationships with other providers affords opportunities for Hospice Services, Inc., to learn from other providers and to share its own expertise.

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix A:
Boundary and Confidentiality Issues for Rural and Frontier Hospices



Appendix A: Boundary and Confidentiality Issues for Rural and Frontier Hospices

Working in hospice in a rural area provides unique benefits and daunting challenges. Many professionals find that the intricate web of relationships in a rural community is an advantage. Rural patients, families and providers benefit from many kinds of support that derive from small communities where folks are often fiercely independent and resistant to interventions from outsiders yet inter-connected and ready to help each other in extraordinary ways.

To be able to ease the suffering of friends, co-workers, neighbors, church members and others interwoven into our own community is deeply satisfying. As patients reach the end of their lives and find that they need help, fear and distrust may be eased if they are helped by those they know. Examples of the community connection are plentiful:

- Consistent with a focus on community service, high school students in Littleton, NH, worked with their shop teacher to build a wheelchair ramp for a hospice patient who would not accept charity and who otherwise would have been confined to his home;
- Thanks to Hospice of the Plains staff in Wray, CO, a plumber repaired a broken toilet while the patient slept — at the request of the patient's wife, who did not want her husband to know about the problem;
- Just before a gathering storm in Akron, CO, a social worker from Hospice of the Plains drove a riding mower and a farm truck full of wheat into a barn at a time when no one at the patient's home was able to drive these vehicles to shelter.

Knowing many people in a community results in referrals from quarters that might never have considered hospice care, as well as key information about a patient's circumstances or family dynamics. The tight and interwoven bonds of a smaller community ease the ache of our own grief when a patient who is close to us dies. But there are also great challenges.

Professionals enter into relationships with patients and families holding special privileges and power. This imbalance of power requires that professionals honor a covenant to act in the patients' best interest. In contrast, contractual relationships are founded on an assumption of distrust, with external strategies (such as advance directives) to ensure that an individual is protected from intrusion. Covenantal relationships are based on trust and are durable; they cannot be severed. Hospice care has operated from a covenantal and community-based approach and thus, as an institution, holds a unique covenantal relationship with patients and their families.[26] In a community that shares much common memory, the durability of a covenantal relationship extends beyond the individual even to generations.

Together these covenants, that of professionals and that as an institution, form the foundation for understanding boundary and confidentiality issues between a hospice and the patient and family in its care. Not only the professionals who work in hospice, but volunteers and aides as well must understand and uphold this covenantal relationship.

Most of the literature on professional boundary issues is from mental health professionals, and within that body of information, the vast majority address issues in an urban environment in which professionals have more anonymity, ready access to other resources for referral and more ease in maintaining confidentiality.

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[26] Byock, I. Rediscovering community at the core of the human condition and social covenant. *Hastings Center Report Special Supplement,* 33(2): S40-41, 2003.

Appendix A: Boundary and Confidentiality Issues for Rural and Frontier Hospices

In rural areas overlapping professional and social relationships are inevitable. Caring for a person that you know can be emotionally challenging, yet if a professional chooses not to provide services because he or she knows a patient from a different context, this could mean that the patient gets no help at all.[27] Rural hospices need to address boundary issues differently than their urban counterparts.

Managing confidentiality can be difficult for rural hospices. Not only may friends, neighbors or relatives have a chance to view a patient's medical records by the time the records have gone through the process of dictation, transcription, dispersal to insurance companies and other providers, but a hospice team may, merely by visiting a person in his or her own home, alert neighbors to the patient's status. Further, rural hospice workers need to decide how to use information gathered through informal sources in social settings ("Don't tell him I said this but my brother is selling the morphine that you brought for my mother, and she doesn't know."). And hospice workers need to realize that they will not have the anonymity, with its passive "reverse confidentiality," of their urban counterparts. People will notice the hospice worker crying in his car, or stopping by the municipal bar, or "not holding up well" at a funeral.

Boundary Issues

Recognition and acceptance of the imbalance in power between hospice workers and the patients and families they care for is critical not only for professionals on the hospice team, but for aides and volunteers as well. By being part of the hospice team certain privileges are granted: to enter a person's home, to talk about taboo subjects such as toileting or death, to engage in intimate activities such as bathing, or to learn details of medical history that may tread close to gossip.

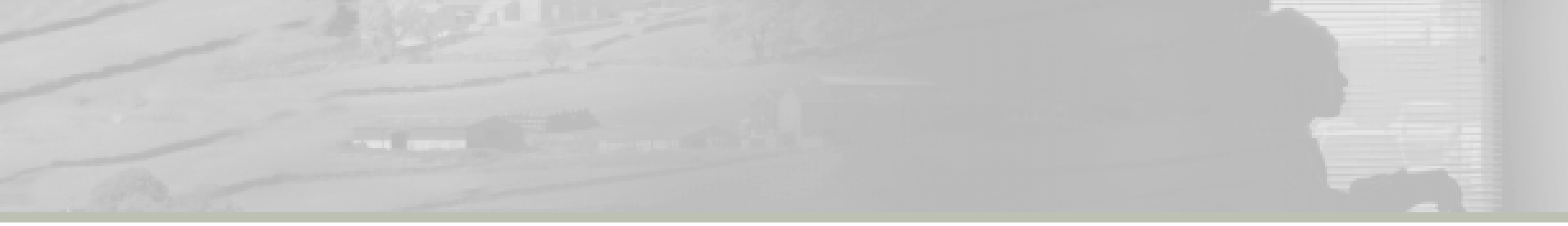
Although most professionals belong to organizations that have clear ethical guidelines, many paraprofessionals have less explicit guidance. Even with clear guidelines there are challenges in knowing exactly how to apply them in rural communities where we are taking care of co-workers, members of the same church, neighbors and even family. We don't have the luxury of referring a neighbor to a different hospice, or to a different interdisciplinary team.

This dense crossing of social and professional networks complicates ordinary interactions. Not accepting a gift may be a social insult. A trivial slip in conversation may reveal that we are taking care of someone's friend in a professional capacity when the friend did not know the patient was dying. An estranged ex-wife may transcribe a dictated note.

The general codes of professional organizations fail to give those of us working in rural communities a practical basis for making decisions day in and day out, and inadvertent boundary crossings and violations are not uncommon. A doctor may have gotten a loan from a banker-patient, an aide may out of concern alert a relative of a patient's illness, a nurse may share a story of personal loss that is still too "tender" in an effort to support a patient's grief, a social worker may unknowingly accept a family heirloom as a gift, a chaplain may find himself romantically attracted to a patient's niece at the bedside.

How, then, can these complexities be addressed in the day-to-day chaos of hospice work? It is helpful for teams to have a model for discussing whether multiple relationships are a safe crossing of boundary lines or a violation of the relationship with a patient. Social worker Marilyn Peterson has described a model in her book, *At Personal Risk*,[28] that involves four interlocking components that make up boundary violations.

[276] Schank, JA, Skovholt, TM, Dual-relationship dilemmas of rural and small-community psychologists. *Professional Psychology: Research and Practice*, 28(1): 44-49, 1997.



1. First, in a boundary violation there is a *reversal of roles*. The client takes care of a professional's needs rather than the professional caring for the client. If, when the nurse shared his story of personal loss, the patient feels a need to comfort the nurse, the roles have been reversed. This may not be a problem if the patient is emotionally strong at the time, but if the patient is harboring a small store of emotional energy, the cost to that patient may be too high.
2. A second feature is that there is a *secret.* A slip of the tongue that alerts a distant relative of a patient's need may have been in the interest of gathering more support for the patient. The hospice worker may not have even thought about a "secret" desire to have more family involvement with a patient in order to ease the stress on the hospice team. Again the secret may remain hidden, may indeed never be known unless problems arise. What problem could arise? What if the patient is dying of AIDS and some family members were purposefully excluded from that knowledge? Or what if long ago there were instances of sexual abuse between the patient and the family member? A well-meaning attempt to help may create a chaotic situation.
3. Then, the client is caught in a *double-bind.* If the patient feels resentful about taking care of the nurse who shares a story of a loss, she has several no-win choices. She could confront the nurse with the dilemma, but that carries the risk of antagonizing someone who has power over the care she will receive. She could choose a different hospice or a different team member if there is such an option in a rural area, but then has to develop a whole new set of relationships. Or she could put up with the current situation using what may be limited emotional energy.
4. Finally, there is an *indulgence of personal privilege*. The chaplain might never have met the patient's niece without the meeting at the bedside. Here it is critical to recognize that covenantal relationships are durable; they don't end when we stop providing direct services. Pursuing a romantic relationship serves the chaplain's interests, not necessarily the niece's. Could such a relationship ever be pursued? This is at best controversial and at worst fraught with peril. Rarely are romantic relationships arising out of caregiving relationships safe and healthy for both parties. The nature of the interactions with family, the difficulties of a particular patient's death and other factors all enter into the picture. Team members need to be able to bring such issues to peers, and need to accept the insight and advice of others.

These four characteristics interlock and come into play in almost every boundary violation. In a rural community there is not the luxury of simply putting physical distance between oneself and a client. Almost certainly paths will cross in other, non-professional settings. This is part of living in a rural area. All of us will cross these boundaries, and anyone who has worked any length of time almost certainly can bring to mind instances when a relationship became "uncomfortable," which in retrospect may have been a boundary violation.

It is critical that interdisciplinary teams be able to discuss boundary issues that arise when caring for patients and families. Sometimes difficulties can be spotted before anything untoward has happened. A team member can point out to the physician who is having financial problems that he had better not try to emotionally bribe the banker. The aide can ask the team if alerting a non-involved family member seems appropriate given the demands

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[276] Peterson, M. *At Personal Risk.* W. W. Norton & Co., 1992.

on the team, or how to go about asking the patient for permission. A policy regarding gifts can be brought up and discussed, but it must be realistic. Are all gifts prohibited, even the offer of coffee or garden vegetables?

The strain of isolation and loneliness that is part and parcel of being a professional, and which is particularly intense in a rural community, needs to be a comfortable topic of discussion so that coping strategies can be brought out for all team members. Particularly if there is a nonjudgmental, problem-solving approach, team members can bring problems to be solved rather than hiding in fear of disciplinary action for human fallibility. Not everything can be excused, but team members can work together to make the painful corrections before the client is harmed further.

Confidentiality

Hospices in rural settings face particular challenges regarding confidentiality. Having a multidisciplinary team increases the odds that somebody on the team knows the patient — if not the professional staff, then the aide or volunteer. "Unseen" workers, from the answering service to the transcriptionist, may know the client and suddenly have access to personal information. A hospice worker walking into a home will reveal information to neighbors who are watching. And how many times, walking out of a home has that concerned neighbor asked how the patient is doing? The social responses of "fine" or "not too well" may disclose far more than the patient wishes. These wishes need to be explicitly recognized, to find out if the patient wants a 'tight' sense of confidentiality or if she is comfortable with general disclosure to a neighbor.

It is helpful to recognize that privacy and confidentiality are not the same. Green and Mason articulate the difference. "Privacy relates to the degree of control a person has over what happens to information about them held by someone else," and confidentiality is the regulation that protects privacy.[29] They go on to point out that absolute confidentiality is not possible and sometimes not desirable (e.g., sharing information between team members). People who live in rural areas are used to a different amount of privacy compared to urban dwellers; they may not even realize that the hospice team will hold information as private.

How then, should rural hospice workers handle confidentiality?

- Don't talk about patients — even without names — outside of work. People can put pieces of information together and recognize another person even without reference to a name.
- Provide for debriefing opportunities for the entire staff. Sometimes confidential information is a burden too great for a person to hold alone.
- Talk with patients about what they want kept private, and any persons who they are concerned might see information (e.g. a niece who works as a transcriptionist).
- Explain to patients that you will not be sharing the information with friends you have in common, your spouse, a mutual pastor, or in other situations in which social and work roles cross over, unless they ask you to do so. This prevents misunderstandings because many times patients assume we will "pass on the news."
- Most mental health practitioners choose to not acknowledge a patient in public unless the patient initiates an interaction, in order to protect confidentiality. In a rural practice this practice needs to be explicitly discussed with patients and families to avoid a situation in which they feel snubbed by the hospice worker.

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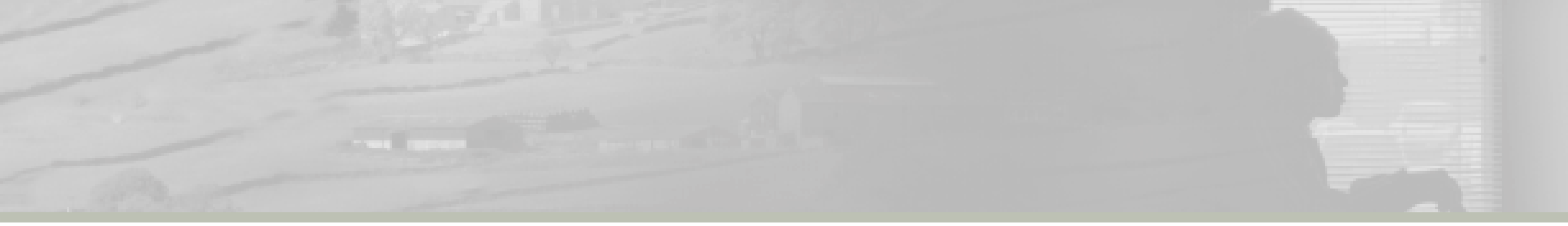
[276] Green, R, Mason, R. Managing confidentiality in rural welfare practice in Australia. *Rural Social Work*, 7(1): 34-43, June 2002.



Summary

Professional codes of ethics do not adequately address the issues for rural hospice workers. The dense social, familial and professional networks in a rural area inevitably overlap, which can be an asset but can also cause festering problems. Some people will not have the words to articulate their own discomfort. Peterson's model offers a framework for teams to discuss boundary concerns. Confidentiality needs to be addressed explicitly with patients and families to avoid misunderstandings.

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix B:
Critical Access Hospitals

Appendix B: Critical Access Hospitals

What is a Critical Access Hospital?

The Critical Access Hospital (CAH) program was created by the Balanced Budget Act of 1997. It was designed to support rural, low-volume, limited-service hospitals that were facing severe financial crises under the Medicare Prospective Payment System (PPS). The Medicare Modernization Act of 2003 (MMA) added some enhancements to the CAH program. Today, there are over 900 hospitals in the United States that have been designated as a CAH.

In order to qualify as a CAH, a hospital must be located in a rural area and more than 35 miles away from another hospital. In areas with mountainous terrain or only secondary roads, the distance requirement may be lowered to 15 miles. Alternatively, states may certify a hospital as a *necessary provider* of services in the area. States' ability to waive the distance requirement through a necessary-provider designation is scheduled to sunset at the end of 2005.

In addition to the above distance requirements, CAHs are limited to 25 beds for acute inpatient services, must provide 24-hour emergency care services, and must maintain an average length of stay of 96 hours or less, unless a longer period is required because of inclement weather or other emergency conditions, or unless a quality improvement organization (formerly known as a PRO) or other equivalent entity, on request, waives the 96-hour restriction. CAHs have flexibility up to the 25-bed limit for swing beds, and may have up to 25 inpatient beds that can be used interchangeably for acute or skilled nursing facility-level care.

Upon designation as a CAH, a hospital meeting these requirements is removed from Medicare's PPS reimbursement and paid by Medicare for 101 percent of its reasonable Medicare allowable costs. For many CAH hospitals, which do not have the volume load to succeed under PPS, the CAH program has been the lifeboat that has allowed them to continue providing quality care to millions of rural Americans.[30]

Background

The Balanced Budget Act of 1997 (BBA), Public Law 105-33, in section 4201, authorized a program called the Medicare Rural Hospital Flexibility Program (Flex Program). The Flex Program is a Federal initiative that provides funding ($25 million in FY 2001) to state governments to:

1. Allow small hospitals the flexibility to reconfigure operations and be licensed as CAHs;
2. Offer cost-based reimbursement for Medicare acute inpatient and outpatient services;
3. Encourage the development of rural-centered health networks; and
4. Offer grants to states to help implement a CAH program in the context of broader initiatives to strengthen the rural health care infrastructure.

The Medicare Modernization Act of 2003 (MMA) reauthorized Medicare's Flex Program to make grants to all states in the amount of $35 million in each of fiscal years 2005 through 2008.[31]

[30] *Rural Roads*, Newsletter of the National Rural Health Association, December 2004.

[31] Fact Sheet, Critical Access Hospital Program, May 2004: www.cms.hhs.gov.

Appendix B: Critical Access Hospitals

The Flex Program is based on two similarly intentioned programs from the early 1990s: the Essential Access Community Hospital and Rural Primary Care Hospital program and the Montana Medical Assistance Facility demonstration project. These programs successfully showed that states, working with their rural communities and providers, could develop networks of limited-service hospitals and other health providers, expand the supply of practitioners, improve the financial position of rural hospitals, and foster the integration of services to improve continuity and avoid duplication.

Critical Access Hospital designation is available in any state that chooses to establish a Flex Program and that provides the Centers for Medicare and Medicaid Services (CMS) with the necessary assurances.[32]

Hospice Services and Critical Access Hospitals

Hospices are beginning to report increased difficulties in working out contractual relationships with CAHs in their service areas. NHPCO reports that CMS has confirmed the following understandings regarding the CAH/Hospice relationship:

1. Hospices *can* contract with CAHs.
2. The hospice pays the CAH for the patient's inpatient stay. CMS does not specify the amount that the hospice pays to the CAH. The contractual arrangement and amount are business decisions between the hospice and the CAH.
3. The hospice may contract for either routine acute care beds or as a part of a swing bed.

Two issues that have arisen with CAHs as they contract with hospices are:

1. Hospice general inpatient days *do* count toward the CAH's per diem, as figured in the annual CAH cost report. Many CAHs are concerned because the daily rate for general inpatient care offered by the hospice and the CAH's reimbursement rate for a day of inpatient care are often hundreds of dollars apart, and the CAH's overall per-diem rate could decrease for all types of inpatient care that are provided if many hospice inpatient days are included in the calculation. Unfortunately, there appears to be no regulatory authority to exclude hospice days from the inpatient day count in the CAH cost report. NHPCO is pursuing a variety of possible solutions to this problem.
2. CAH admission requirements are also a difficulty for hospice providers. The hospice general inpatient level of care is not equivalent to an acute hospital admission, because the hospice general inpatient level of care allows admitting a patient for caregiver breakdown, an admission not familiar to CAHs. Some hospices have had trouble admitting hospice patients to a CAH when caregiver breakdown is the primary reason for the admission.[33]

   (*Note:* for more information on critical access hospitals, see the memo from the Centers for Medicare and Medicaid Services at: *www.cms.hhs.gov/medicaid/survey-cert/121220001.pdf* and the Critical Access Hospitals Factsheet at: *www.cms.hhs.gov/medlearn/cahfactsheet.pdf*.)

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[32] Information provided by Alan Morgan, National Rural Health Association, November, 2004.

[33] National Hospice and Palliative Care Organization Member Communication, November 11, 2004.

CENTER TO ADVANCE PALLIATIVE CARE
National Hospice and Palliative Care Organization
NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix C:

The Medicare Hospice Benefit

Appendix C: The Medicare Hospice Benefit

National Hospice and Palliative Care
Organization

1700 Diagonal Road • Suite 625 • Alexandria, Virginia 22314
703/837-1500 703/837-1233 (fax)

More than 96 percent of hospices in the United States are certified by Medicare. Medicare defines a set of hospice core services, which many hospices surpass through voluntary, community-based efforts.

The Medicare Hospice Benefit, initiated in 1983, is covered under Medicare Part A (hospital insurance). Medicare beneficiaries who choose hospice care receive a full scope of non-curative medical and support services for their terminal illness. Hospice care also supports the family and loved ones of the patient through a variety of services, enhancing the value of the Medicare Hospice Benefit.

The Medicare Hospice Benefit Provides for:

- Physician services
- Nursing care
- Medical appliances and supplies
- Drugs for symptom management and pain relief
- Short-term inpatient and respite care
- Homemaker and home health aide services
- Counseling
- Social work services
- Spiritual care
- Volunteer participation
- Bereavement services
- Physical therapy, occupational therapy and speech/language pathology services

Who is Eligible?

Medicare has three key eligibility criteria:

- The patient’s doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with a life expectancy of six months or less, if the disease runs its normal course;
- The patient chooses to receive hospice care rather than curative treatments for his or her illness; and
- The patient enrolls in a Medicare-approved hospice program.

Appendix C: The Medicare Hospice Benefit

Payment for Hospice:

- Medicare pays the hospice program a *per diem* rate that is intended to cover virtually all expenses related to addressing the patient's terminal illness.
- Because patients require differing intensities of care during the course of their disease, the Medicare Hospice Benefit affords patients four levels of care to meet their needs: Routine Home Care, Continuous Home Care, Inpatient Respite Care and General Inpatient Care.
- Ninety-five percent of hospice care is provided at the routine home care level, which is reimbursed at approximately $118 per day.
- Hospice benefit rates have increased annually based on the Hospital Market Basket Index. With the advent of costly new drugs and treatments like palliative radiation, the average cost to hospices has risen much faster than the reimbursement rates.
- Hospices that are Medicare certified must offer all services required to palliate the terminal illness, even if the patient is not covered by Medicare and does not have the ability to pay.

August, 2004

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix D:

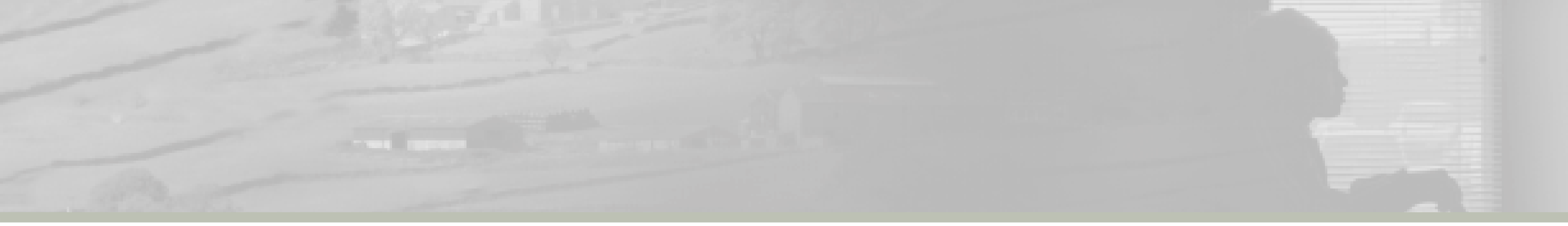
List of America's Frontier Counties

Appendix D: List of America's Frontier Counties

State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Alabama	4,447,100	Conecuh	14,089	16.6	8.80%	1.40%
		Greene	9,974	15.4		
		Wilcox	13,183	14.8		
Alaska	626,932	Aleutians East	2,697	1.1	52.30%	88.00%
		Aleutians West	5,465	1.2		
		Bethel	16,006	0.4		
		Bristol Bay	1,258	2.5		
		Dillingham	1,893	0.1		
		Fairbanks North Star	82,842	11.2		
		Haines	2,392	1		
		Juneau	30,711	11.3		
		Kenai Peninsula	2,697	0.4		
		Ketchikan Gateway	14,070	11.4		
		Kodiak Island	13,913	2.1		
		Lake & Peninsula	1,823	0.1		
		Matanuska-Susitna	59,322	2.4		
		Nome	9,196	0.4		
		North Slope	7,385	0.1		
		Northwest Arctic	7,208	0.2		
		Prince of Wales	6,146	0.8		
		SE Fairbanks	6,174	0.2		
		Sitka	8,835	3.1		
		Skagway-Yakutat-Ango	4,244	0.3		
		Valdez-Cordova	10,195	0.3		
		Wade-Hampton	7,028	0.4		
		Wrangell-Petersburg	6,684	1.1		
		Yukon-Koyukuk	6,551	0		
Arizona	5,130,632	Apache	69,423	6.23	6.70%	86.00%
		Cochise	117,755	19.1		
		Coconino	116,320	6.2		
		Gila	51,335	10.8		
		Graham	33,489	7.2		
		Greenlee	8,547	4.6		
		La Paz	19,715	4.4		
		Mohave	155,032	11.6		
		Navajo	97,470	9.8		
		Pima	843,746	91.9		
		Santa Cruz	38,381	31		
		Yavapai	167,517	20.6		
		Yuma	160,026	29		
Arkansas	2,673,400	Arkansas	20,749	21	14.00%	28.00%
		Bradley	12,60019.4			
		Calhoun	5,744	9.1		
		Cleveland	8,571	14.3		
		Dallas	9,210	13.8		
		Desha	15,341	20.1		
		Fulton	11,642	18.8		
		Lafayette	8,559	16.2		
		Lee	12,580	20.9		
		Madison	14,243	17		
		Monroe	10,254	16.9		

Appendix D: List of America's Frontier Counties

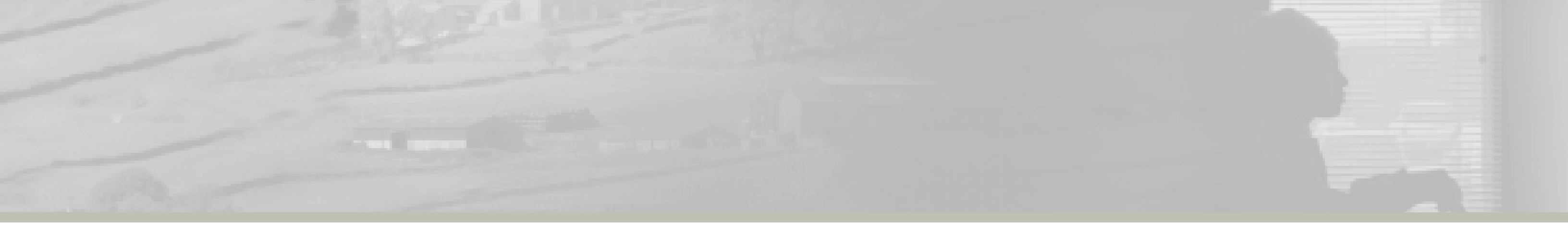
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Arkansas, cont.		Montgomery	9,245	11.8		
		Nevada	9,955	16.1		
		Newton	8,608	10.5		
		Perry	10,209	18.5		
		Pike	11,303	18.7		
		Prairie	9,539	14.8		
		Scott	10,996	12.3		
		Searcy	8,261	12.4		
		Stone	11,499	18.9		
		Woodruff	8,741	14.9		
California	33,871,648	Alpine	1,208	1.6	2.00%	26.00%
		Colusa	18,804	16.3		
		Imperial	142,361	34.1		
		Inyo	17,945	1.8		
		Lassen	33,828	7.4		
		Mariposa	17,130	11.8		
		Mendicino	86,265	24.6		
		Modoc	9,449	2.4		
		Mono	12,853	4.2		
		Plumas	20,824	8.2		
		Sierra	3,555	3.7		
		Siskiyou	44,301	7		
		Tehama	56,039	19		
		Trinity	13,022	4.1		
		Tuolumne	54,501	24.4		
Colorado	4,301,261	Alamosa	14,966	20.7	11.00%	67.00%
		Archuleta	9,898	7.3		
		Baca	4,517	1.8		
		Bent	5,998	4		
		Chaffee	16,242	16		
		Cheyenne	2,231	1.3		
		Conejos	8,400	6.5		
		Costilla	3,663	3		
		Crowley	5,518	7		
		Custer	3,503	4.7		
		Dolores	1,844	1.7		
		Elbert	19,872	10.7		
		Garfield	43,791	14.9		
		Grand	12,442	6.7		
		Gunnison	13,956	4.3		
		Hinsdale	790	0.7		
		Huerfano	7,862	4.9		
		Jackson	1,577	1		
		Kiowa	1,622	0.9		
		Kit Carson	8,011	3.7		
		Lake	7,812	20.7		
		Las Animas	15,207	3.2		
		Lincoln	6,087	2.4		
		Mineral	831	0.9		
		Moffat	13,184	2.8		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Colorado, cont.		Montezuma	23,830	11.7		
		Montrose	33,432	14.9		
		Otero	20,311	16.1		
		Ouray	3,742	6.9		
		Park	14,523	6.6		
		Phillips	4,480	6.5		
		Pitkin	14,872	15.3		
		Prowers	14,483	8.8		
		Rio Blanco	5,986	1.9		
		Rio Grande	12,413	13.6		
		Routt	19,690	8.3		
		Saguache	5,917	1.9		
		San Juan	558	1.4		
		San Miguel	6,594	5.1		
		Sedgwick	2,747	5		
		Washington	4,926	2		
		Yuma	9,841	4.2		
Florida	15,982,378	Lafayette	7,022	12.9	0.21%	4.40%
		Glades	10,576	13.7		
		Liberty	7,021	8.4		
Georgia	8,186,453	Baker	4,074	11.9	1.20%	10.00%
		Calhoun	6,320	22.6		
		Charlton	10,282	13.2		
		Clay	3,357	17.2		
		Clinch	6,878	8.5		
		Echols	3,754	9.3		
		Glascock	2,556	17.8		
		Hancock	10,076	21.3		
		Marion	7,144	19.5		
		Quitman	2,598	17.1		
		Randolph	7,791	18.2		
		Stewart	5,252	11.4		
		Talbot	6,498	17		
		Taliaferro	2,077	10.7		
		Webster	2,390	11.4		
		Wheeler	6,179	20.7		
		Wilcox	8,577	22.6		
Idaho	1,293,953	Adams	3,476	2.5	19.40%	59.00%
		Bear Lake	6,411	6.6		
		Benewah	9,171	11.8		
		Blaine	18,991	7.2		
		Boise	6,670	3.5		
		Boundary	9,871	7.8		
		Butte	2,899	1.3		
		Camas	991	0.9		
		Caribou	7,304	4.1		
		Cassia	21,416	8.3		
		Clark	1,022	0.6		
		Clearwater	8,930	3.6		
		Custer	4,342	0.9		

Appendix D: List of America's Frontier Counties

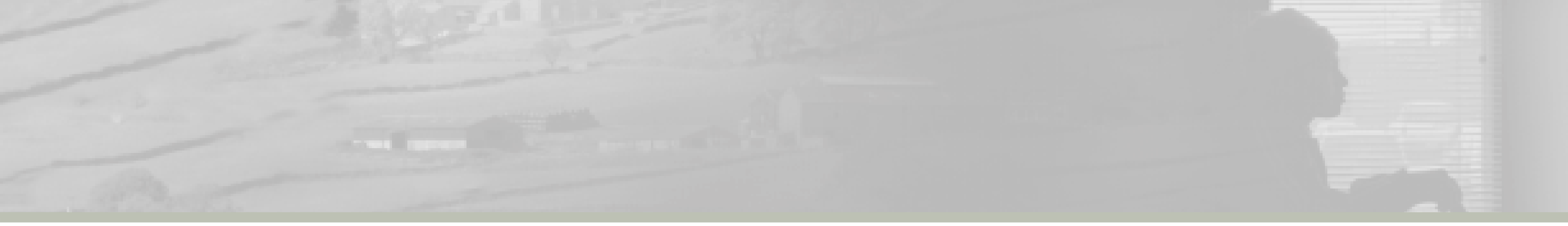
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Idaho, cont.		Elmore	29,130	9.5		
		Fremont	11,819	6.3		
		Gooding	14,155	19.4		
		Idaho	15,511	1.8		
		Lemhi	7,806	1.7		
		Lincoln	4,044	3.4		
		Oneida	4,125	3.4		
		Owyhee	10,644	1.4		
		Power	7,538	5.4		
		Shoshone	13,771	5.2		
		Teton	5,999	13.3		
		Valley	7,651	2.1		
		Washington	9,977	6.9		
Illinois	12,419,293	Calhoun	5,084	20	0.42%	4.90%
		Hamilton	8,621	19.8		
		Pike	17,384	20.9		
		Pope	4,413	11.9		
		Schuyler	7,189	16.5		
Kansas	2,688,418	Barber	5,307	4.7	9.60%	53.00%
		Chase	3,030	3.9		
		Chautauqua	4,359	6.8		
		Cheyenne	3,165	3.1		
		Clark	2,390	2.5		
		Comanche	1,967	2.5		
		Decatur	3,472	3.9		
		Doniphan	8,249	21		
		Edwards	3,449	5.5		
		Elk	3,261	5		
		Ellsworth	6,525	9.1		
		Gove	3,068	2.9		
		Graham	2,946	3.3		
		Gray	5,904	6.8		
		Greeley	1,534	2		
		Greenwood	7,673	6.7		
		Hamilton	2,670	2.7		
		Harper	6,536	8.2		
		Haskell	4,307	7.5		
		Hodgeman	2,085	2.4		
		Jewell	3,791	4.2		
		Kearny	4,531	5.2		
		Kingman	8,673	10		
		Kiowa	3,278	4.5		
		Lane	2,155	3		
		Lincoln	3,578	5		
		Logan	3,046	2.8		
		Marshall	10,965	12.1		
		Meade	4,631	4.7		
		Mitchell	6,932	9.9		
		Morris	6,104	8.8		
		Morton	3,496	4.8		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Kansas, cont.		Ness	3,454	3.2		
		Osborne	4,452	5		
		Ottawa	6,163	8.5		
		Pawnee	7,233	9.6		
		Phillips	6,001	6.8		
		Rawlins	2,966	2.8		
		Republic	5,835	8.1		
		Rooks	5,685	6.4		
		Rush	3,551	4.9		
		Russell	7,370	8.3		
		Scott	5,120	7.1		
		Sheridan	2,813	3.1		
		Sherman	6,760	6.4		
		Smith	4,536	5.1		
		Stafford	4,78	96		
		Stanton	2,406	3.5		
		Stevens	5,463	7.5		
		Thomas	8,180	7.6		
		Trego	3,319	3.7		
		Wabaunsee	6,885	8.6		
		Wallace	1,749	1.9		
		Washington	6,483	7.2		
		Wichita	2,531	3.5		
		Woodson	3,788	7.6		
Kentucky	4,041,769	Hickman	5,262	21.6	0.27%	1.60%
		Robertson	2,266	22.7		
Louisiana	4,468,976	Cameron	9,991	7.6	0.22%	1.00%
Maine	4,919,479	Aroostook	73,938	11.1	16.00%	31.25%
		Franklin	29,467	17.4		
		Pscataquis	17,235	4.3		
		Somerset	50,888	13		
		Washington	33,941	13.2		
Michigan	9,938,444	Keweenaw	2,190	4	0.02%	
		Luce	6,769	7		
		Ontonagon	7,476	6		
		Schoolcraft	8,824	7		
Minnesota	4,919,479	Aitkin	15,301	8.4	15.00%	41.00%
		Beltrami	39,650	15.8		
		Big Stone	5,820	11.7		
		Cass	27,150	13.5		
		Clearwater	8,423	8.5		
		Cook	5,168	3.6		
		Cottonwood	12,167	19		
		Grant	6,289	11.5		
		Hubbard	18,376	19.9		
		Itasca	43,992	16.5		
		Jackson	11,268	16.1		
		Kittson	5,285	4.8		
		Koochiching	14,355	4.6		
		Lac Qui Parle	8,067	10.5		

Appendix D: List of America's Frontier Counties

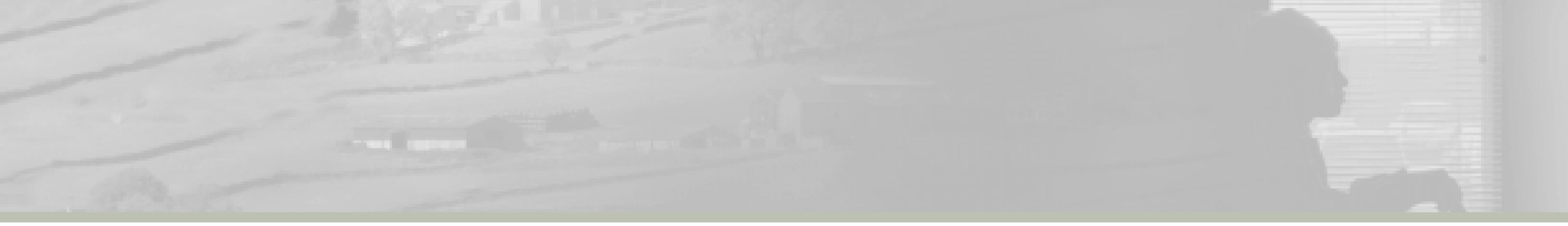
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Minnesota, cont.		Lake	11,058	5.3		
		Lake Of Woods	4,522	3.5		
		Lincoln	6,429	12		
		Mahnomen	5,190	9.3		
		Marshall	10,155	5.7		
		Murray	9,165	13		
		Norman	7,442	8.5		
		Pine	26,530	18.8		
		Polk	31,369	15.9		
		Pope	11,236	16.8		
		Red Lake	4,299	10		
		Redwood	16,815	19.1		
		Renville	17,154	17.5		
		Rock	9,721	20.1		
		Roseau	16,338	9.8		
		Stevens	10,053	17.9		
		Swift	11,956	16.1		
		Traverse	4,134	7.2		
		Wilkin	7,138	9.5		
		Yellow Medicine	11,080	14.6		
		Saint Louis	200,528	32.2		
		East Ottertail	57,159	28.9		
Mississippi	2,844,658	Amite	13,599	18.6	6.10%	15.80%
		Benton	8,026	19.7		
		Carroll	10,769	17.1		
		Franklin	8,448	15		
		Greene	13,299	18.7		
		Issaquena	2,299	5.5		
		Jefferson	2,274	18.8		
		Kemper	9,740	13.6		
		Noxubee	10,453	18.1		
		Perry	12,548	18.8		
		Sharkey	6,580	15.4		
		Tunica	9,227	20.3		
		Wilkinson	10,312	15.2		
Missouri	5,595,212	Carter	5,941	11.7	0.87%	6.00%
		Chariton	8,438	11.2		
		Holt	5,351	11.6		
		Knox	4,361	8.6		
		Mercer	3,757	8.3		
		Shannon	8,324	8.3		
		Worth	2,382	8.9		
Montana	902,195	Beaverhead	9,202	1.7	54.10%	87.50%
		Big Horn	12,671	2.5		
		Blaine	7,009	1.7		
		Broadwater	4,385	3.7		
		Carbon	9,552	4.7		
		Carter	1,360	0.4		
		Chouteau	5,970	1.5		
		Custer	11,696	3.1		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Montana, cont.		Daniels	2,017	1.4		
		Dawson	9,059	3.8		
		Deer Lodge	9,417	12.8		
		Fallon	2,837	1.8		
		Fergus	11,893	2.7		
		Flathead	74,471	14.6		
		Garfield	1,279	0.3		
		Glacier	13,247	4.4		
		Golden Valley	1,042	0.9		
		Granite	2,830	1.6		
		Hill	16,673	5.8		
		Jefferson	10,049	6.1		
		Judith Basin	2,329	1.2		
		Lake	26,507	17.7		
		Lewis & Clark	55,716	16.1		
		Liberty	2,158	1.5		
		Lincoln	18,837	5.2		
		Madison	6,851	1.9		
		McCone	1,977	0.7		
		Meagher	1,932	0.8		
		Mineral	3,884	3.2		
		Musselshell	4,497	2.4		
		Park	15,694	5.6		
		Petroleum	494	0.3		
		Phillips	4,601	0.9		
		Powell	7,180	3.1		
		Prairie	1,199	0.7		
		Ravalli	36,070	15.1		
		Richland	9,667	4.6		
		Roosevelt	10,620	4.5		
		Rosebud	9,383	1.9		
		Sanders	10,227	3.7		
		Sheridan	4,105	2.4		
		Stillwater	8,195	4.6		
		Sweet Grass	3,609	1.9		
		Teton	6,445	2.8		
		Toole	5,267	2.8		
		Treasure	861	0.9		
		Valley	7,675	1.6		
		Wheatland	2,259	1.6		
		Wibaux	1,068	1.2		
		Y'stone Nat'l	NA	NA		
Nebraska	1,711,263	Antelope	7,452	8.7	16.70%	62.00%
		Arthur	444	0.6		
		Banner	819	1.1		
		Blaine	583	0.8		
		Boone	6,259	9.1		
		Box Butte	12,158	11.3		
		Boyd	2,438	4.5		
		Brown	3,525	2.9		

Appendix D: List of America's Frontier Counties

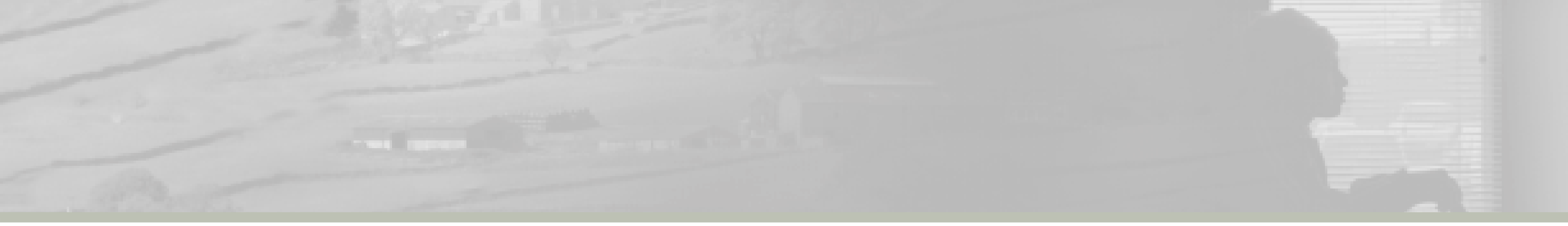
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Nebraska, cont.		Chase	4,068	4.5		
		Cherry	6,148	1		
		Cheyenne	9,830	8.2		
		Clay	7,039	12.3		
		Custer	11,793	4.6		
		Dawes	9,060	6.5		
		Deuel	2,098	4.8		
		Dundy	2,292	2.5		
		Fillmore	6,634	11.5		
		Franklin	3,574	6.2		
		Frontier	3,099	3.2		
		Furnas	5,324	7.4		
		Garden	2,292	1.3		
		Garfield	1,902	3.3		
		Gosper	2,143	4.7		
		Grant	747	1		
		Greeley	2,714	4.8		
		Hamilton	9,403	17.3		
		Harlan	3,786	6.8		
		Hayes	1,068	1.5		
		Hitchcock	3,111	4.4		
		Holt	11,551	4.8		
		Hooker	783	1.1		
		Howard	6,567	11.5		
		Johnson	4,488	11.9		
		Keith	8,875	8.4		
		Keya Paha	983	1.3		
		Kimball	4,089	4.3		
		Knox	9,374	8.5		
		Lincoln	34,632	13.5		
		Logan	774	1.4		
		Loup	712	1.2		
		McPherson	533	0.6		
		Merrick	8,204	16.9		
		Morrill	5,440	3.8		
		Nance	4,038	9.2		
		Nemaha	7,576	18.5		
		Nuckolls	5,057	8.8		
		Pawnee	3,087	7.1		
		Perkins	3,200	3.6		
		Polk	5,639	12.8		
		Rock	1,756	1.7		
		Sheridan	6,198	2.5		
		Sherman	3,318	5.9		
		Sioux	1,475	0.7		
		Thayer	6,055	10.5		
		Thomas	729	1		
		Valley	4,647	8.2		
		Webster	4,061	7.1		
		Wheeler	886	1.5		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Nevada	1,998,257	Churchill	23,982	4.9	9.50%	76.00%
		Elko	45,291	2.6		
		Esmeralda	971	0.3		
		Eureka	1,651	0.4		
		Humboldt	16,106	1.7		
		Lander	5,794	1.1		
		Lincoln	4,165	0.4		
		Lyon	34,501	17.3		
		Mineral	5,071	1.4		
		Nye	32,485	1.8		
		Pershing	6,693	1.1		
		Storey	3,399	12.9		
		White Pine	9,181	1		
New Hampshire	1,235,786	Coos	33,111	18.4	2.67%	10.00%
New Mexico	1,819,046	Catron	3,543	0.5	42.00%	78.00%
		Chaves	61,382	10.1		
		Cibola	25,595	5.6		
		Colfax	14,189	3.8		
		De Baca	2,240	1		
		Eddy	51,658	12.4		
		Grant	31,002	7.8		
		Guadalupe	4,680	1.5		
		Harding	810	0.4		
		Hidalgo	5,932	1.7		
		Lea	55,511	12.6		
		Lincoln	19,411	4		
		Luna	25,016	1.7		
		Mckinley	74,798	12.6		
		Mora	5,180	4		
		Otero	62,298	8.4		
		Quay	10,155	13.7		
		Rio Arriba	41,190	2.7		
		Roosevelt	18,018	9.4		
		San Juan	113,801	3.5		
		San Miguel	30,126	7		
		Sierra	13,270	7.4		
		Socorro	18,078	20.6		
		Taos	29,979	6.4		
		Torrance	16,911	3.2		
		Union	4,173	2.7		
New York	18,976,457	Essex	38,851	21.6	0.20%	3.22%
		Hamilton	5,379	3.1		
North Carolina	8,049,313	Hyde	5,826	9.5	0.25%	3.00%
		Jones	10,381	22		
		Tyrrell	4,149	10.6		
North Dakota	642,200	Adams	2,593	2.6	47.60%	90.56%
		Barnes	11,775	7.9		
		Benson	6,964	5		
		Billings	888	0.8		
		Bottineau	7,149	4.3		

Appendix D: List of America's Frontier Counties

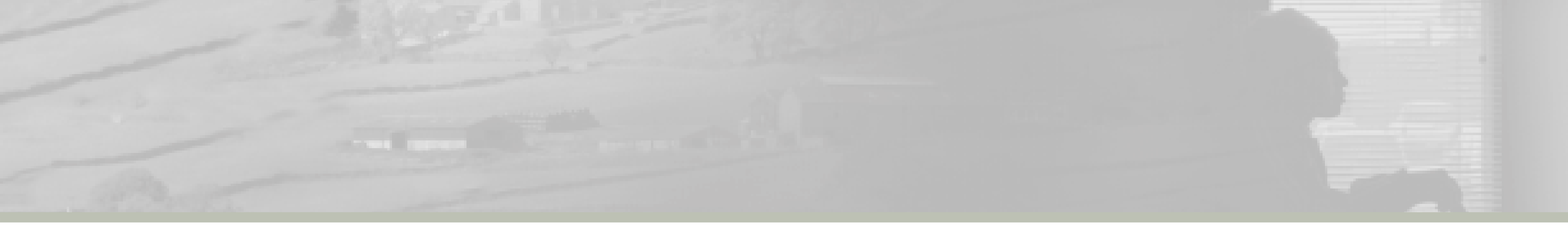
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
North Dakota, cont.		Bowman	3,242	2.8		
		Burke	2,242	2		
		Cavalier	4,831	3.2		
		Dickey	5,757	5.1		
		Divide	2,283	1.8		
		Dunn	3,600	1.8		
		Eddy	2,757	4.4		
		Emmons	4,331	2.9		
		Foster	3,759	5.9		
		Golden Valley	1,924	1.9		
		Grant	2,841	1.7		
		Griggs	2,754	3.9		
		Hettinger	2,715	2.4		
		Kidder	2,753	2		
		La Moure	4,701	4.1		
		Logan	2,308	2.3		
		McHenry	5,987	3.2		
		McIntosh	3,390	3.5		
		McKenzie	5,737	2.1		
		McLean	9,311	4.4		
		Mercer	8,644	8.3		
		Morton	25,303	13.1		
		Mountrail	6,631	3.6		
		Nelson	3,715	3.8		
		Oliver	2,065	2.9		
		Pembina	8,585	7.7		
		Pierce	4,675	4.6		
		Ramsey	12,066	10.2		
		Ransom	5,890	6.8		
		Renville	2,610	3		
		Richland	17,998	12.5		
		Rolette	13,674	15.2		
		Sargent	4,366	5.1		
		Sheridan	1,710	1.8		
		Sioux	4,044	3.7		
		Slope	767	0.6		
		Steele	2,258	3.2		
		Stutsman	21,908	9.9		
		Towner	2,876	2.8		
		Traill	8,477	9.8		
		Walsh	12,389	9.7		
		Wells	5,102	4		
		Williams	19,761	9.5		
Oklahoma	3,450,654	Alfalfa	6,105	7	12.20%	46.00%
		Atoka	13,879	14.2		
		Beaver	5,857	3.2		
		Blaine	11,976	12.9		
		Choctaw	15,342	19.8		
		Cimarron	3,148	1.7		
		Coal	6,031	11.6		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Oklahoma, cont.		Cotton	6,614	10.4		
		Craig	14,950	19.6		
		Dewey	4,743	4.7		
		Ellis	4,075	3.3		
		Grant	5,144	5.1		
		Greer	6,061	9.5		
		Harmon	3,283	6.1		
		Harper	3,562	3.4		
		Haskell	11,792	20.4		
		Hughes	14,154	17.5		
		Jefferson	6,818	9		
		Johnston	10,513	16.3		
		Kingfisher	13,926	15.4		
		Kiowa	10,227	10.1		
		Latimer	10,692	14.8		
		Love	8,831	17.1		
		Major	7,545	7.9		
		McCurtain	34,402	18.6		
		Noble	11,411	15.6		
		Nowata	10,569	18.7		
		Okfuskee	11,814	18.9		
		Osage	44,437	19.7		
		Pushmataha	11,667	8.4		
		Roger Mills	3,436	3		
		Texas	20,107	9.9		
		Tillman	9,287	10.7		
		Washita	11,508	11.5		
		Woods	9,089	7.1		
		Woodward	18,486	14.9		
Oregon	3,421,399	Baker	16,206	53%		
		Crook	18,047	6		
		Gilliam	2,118	2		
		Grant	7,781	1		
		Harney	7,383	1		
		Lake	7,151	1		
		Malheur	28,480	3		
		Morrow	10,987	5		
		Sherman	1,773	2		
		Wallowa	7,189	2		
		Wheeler	1,547	1		
Pennsylvania	12,281,054	Cameron	5,974	14	0.3%	
		Forest	4,939	11		
		Potter	17,112	16		
		Sullivan	6,013	14		
South Dakota	754,844	Aurora	3,058	4.3	42.10%	81.00%
		Beadle	17,023	13.5		
		Bennett	3,5743			
		Bon Homme	7,260	12.9		
		Brule	5,364	6.5		
		Buffalo	2,032	4.3		

Appendix D: List of America's Frontier Counties

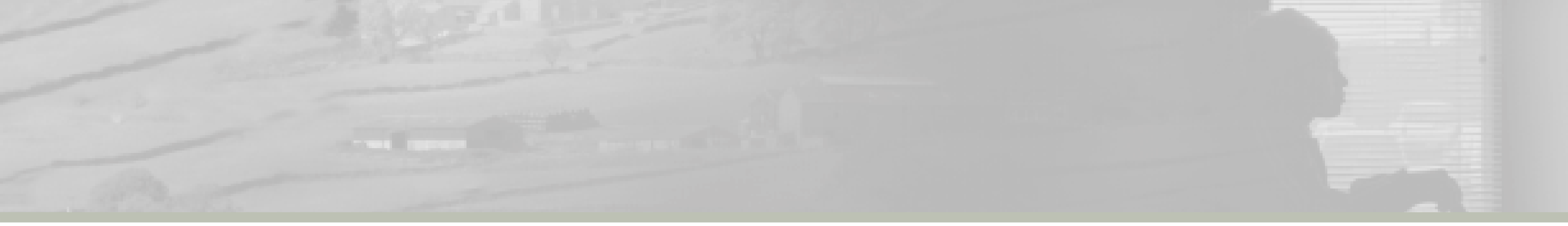
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
South Dakota, cont.	Butte	9,094	4			
		Campbell	1,782	2.4		
		Charles Mix	9,350	8.5		
		Clark	4,143	4.3		
		Corson	4,181	1.7		
		Custer	7,275	4.7		
		Day	6,267	6.1		
		Deuel	4,498	7.2		
		Dewey	5,972	2.6		
		Douglas	3,458	8		
		Edmunds	4,367	3.8		
		Fall River	7,453	4.3		
		Faulk	2,640	2.6		
		Grant	7,847	11.5		
		Gregory	4,792	4.7		
		Haakon	2,196	1.2		
		Hamlin	5,540	10.9		
		Hand	3,741	2.6		
		Hanson	3,139	7.2		
		Harding	1,353	0.5		
		Hutchinson	8,075	9.9		
		Hyde	1,671	1.9		
		Jackson	2,930	1.6		
		Jerauld	2,295	4.3		
		Jones	1,193	1.2		
		Kingbury	5,815	6.9		
		Lake	11,276	20		
		Lyman	3,895	2.4		
		Marshall	4,576	5.5		
		McCook	5,832	10.1		
		McPherson	2,904	2.6		
		Meade	24,253	7		
		Mellette	2,083	1.6		
		Miner	2,884	5.1		
		Moody	6,595	12.7		
		Perkins	3,363	1.2		
		Potter	2,693	3.1		
		Roberts	10,016	9.1		
		Sanborn	2,675	4.7		
		Shannon	12,466	6		
		Spink	7,454	5		
		Stanley	2,772	1.9		
		Sully	1,556	1.5		
		Todd	9,050	6.5		
		Tripp	6,430	4		
		Turner	8,849	14.3		
		Walworth	5,974	8.4		
		Ziebach	2,519	1.3		
Tennessee	5,689,283	Perry	7,631	18.4	0.27%	2.10%
		Van Buren	5,508	20.2		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Texas	20,851,820	Andrews	13,004	8.7	5.45%	51.57%
		Archer	8,854	9.7		
		Armstrong	2,148	2.4		
		Bailey	6,594	8		
		Baylor	4,093	4.7		
		Blanco	8,418	11.8		
		Borden	729	0.8		
		Bosque	17,204	17.4		
		Brewster	8,866	1.4		
		Briscoe	1,790	2		
		Brooks	7,976	8.5		
		Callahan	12,905	14.4		
		Carson	6,516	7.1		
		Castro	8,285	9.2		
		Childress	7,688	10.8		
		Clay	11,006	10		
		Cochran	3,730	4.8		
		Coke	3,864	4.3		
		Coleman	9,235	7.3		
		Collingsworth	3,206	3.5		
		Colorado	20,390	21.2		
		Comanche	14,026	15		
		Concho	3,966	4		
		Cottle	1,904	2.1		
		Crane	3,996	5.1		
		Crockett	4,099	1.5		
		Crosby	7,072	7.9		
		Culberson	2,975	0.8		
		Dallam	6,222	4.1		
		Dawson	14,985	16.6		
		Deaf Smith	18,561	12.4		
		Delta	5,327	19.2		
		Dickens	2,762	3.1		
		Dimmit	10,248	7.7		
		Donley	3,828	4.1		
		Duval	13,120	7.3		
		Eastland	18,297	19.2		
		Edwards	2,162	1		
		Fisher	4,872	4.8		
		Floyd	7,771	7.7		
		Foard	1,406	2.3		
		Freestone	17,867	20.4		
		Frio	16,252	14.2		
		Gaines	14,467	9.6		
		Garza	4,872	5.4		
		Gillespie	20,814	19.6		
		Glasscock	1,406	1.6		
		Goliad	6,928	8.1		
		Gonzales	18,628	17.4		
		Hall	3,782	4.2		

Appendix D: List of America's Frontier Counties

State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Texas, cont.		Hamilton	8,229	9.8		
		Hansford	5,369	5.8		
		Hardeman	11,724	6.8		
		Hartley	5,537	3.8		
		Haskell	6,093	6.7		
		Hemphill	3,351	3.7		
		Houston	23,185	18.8		
		Hudspeth	3,344	0.7		
		Irion	1,771	1.7		
		Jack	8,763	9.6		
		Jackson	14,391	17.4		
		Jeff Davis	2,207	1		
		Jim Hogg	5,281	4.6		
		Jones	20,785	32.3		
		Karnes	15,446	20.6		
		Kenedy	414	0.3		
		Kent	859	1		
		Kimble	4,468	3.6		
		King	356	0.4		
		Kinney	3,379	2.5		
		Knox	4,253	5		
		La Salle	5,866	3.9		
		Lamb	14,709	14.5		
		Lavaca	19,210	19.8		
		Leon	15,335	14.3		
		Lipscomb	3,057	3.3		
		Live Oak	12,309	11.9		
		Llano	17,044	18.2		
		Loving	67	0.1		
		Lynn	6,550	7.3		
		Martin	4,746	5.2		
		Mason	3,738	4		
		McCulloch	8,205	7.7		
		McMullen	851	0.8		
		Menard	2,360	2.6		
		Mills	5,151	6.9		
		Mitchell	9,698	10.7		
		Montague	19,117	20.5		
		Motley	1,426	1.4		
		Newton	15,072	16.2		
		Nolan	15,802	17.3		
		Ochiltree	9,006	9.8		
		Oldham	2,185	1.5		
		Parmer	10,016	11.4		
		Pecos	16,809	3.5		
		Presidio	7,304	1.9		
		Reagan	3,326	2.8		
		Real	3,047	4.4		
		Red River	14,314	13.6		
		Reeves	13,137	5		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Texas, cont.		Refugio	7,828	10.2		
		Roberts	887	1		
		Robertson	16,000	18.7		
		Runnels	11,495	10.9		
		Sabine	10,469	21.4		
		San Augustine	8,946	16.9		
		San Saba	6,186	5.5		
		Schleicher	2,935	2.2		
		Scurry	16,361	18.1		
		Shackelford	3,302	3.6		
		Sherman	3,186	3.5		
		Stephens	9,674	10.8		
		Sterling	1,393	1.5		
		Stonewall	1,693	1.8		
		Sutton	4,077	2.8		
		Swisher	8,378	9.3		
		Terrell	1,081	0.5		
		Terry	12,761	14.3		
		Throckmorton	1,850	2		
		Trinity	13,779	19.9		
		Upton	3,404	2.7		
		Uvalde	25,926	16.7		
		Val Verde	44,856	14.2		
		Ward	10,909	13.1		
		Wheeler	5,284	5.8		
		Wilbarger	14,676	15.1		
		Winkler	7,173	8.5		
		Yoakum	7,322	9.2		
		Young	17,943	19.5		
		Zapata	12,182	12.2		
		Zavela	11,600	8.9		
Utah	2,233,169	Beaver	6,005	2.3	1.30%	79.00%
		Box Elder	42,745	7.5		
		Carbon	20,422	13.8		
		Daggett	921	1.3		
		Duchesne	14,371	4.4		
		Emery	10,860	2.4		
		Garfield	4,735	0.9		
		Grand	8,485	2.3		
		Iron	33,779	10.2		
		Juab	8,238	2.4		
		Kane	6,046	1.5		
		Millard	12,405	1.9		
		Morgan	7,129	11.7		
		Piute	1,435	1.9		
		Rich	1,961	1.9		
		San Juan	14,413	1.8		
		Sanpete	22,763	14.3		
		Sevier	18,842	9.9		
		Summit	29,736	15.9		

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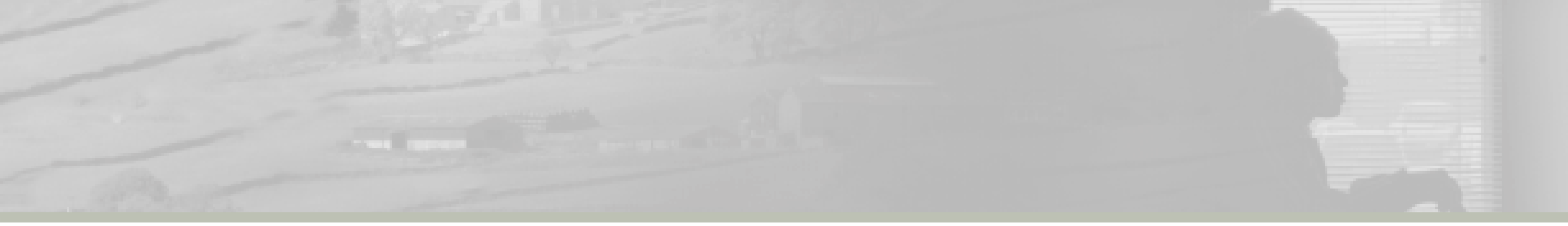
State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Utah, cont.		Tooele	40,735	5.9		
		Uintah	25,224	5.6		
		Wasatch	15,215	12.9		
		Wayne	2,509	1		
Virginia	7,078,515	Bath	5,048	9.5	0.30%	2.90%
		Bland	6,871	19.1		
		Craig	5,091	15.4		
		Highland	2,536	6.1		
Vermont	608,827	Essex	6,459	9.7	0.50%	1.00%
Washington	5,894,121	Adams	16,428	8.5	6.70%	43.58%
		Columbia	4,064	4.7		
		Douglas	32,603	17.9		
		Ferry	7,260	3.3		
		Garfield	2,397	3.4		
		Grant	74,698	27.9		
		Jefferson	25,953	14.3		
		Kittitas	33,362	14.5		
		Klickitat	19,161	10.2		
		Lincoln	10,184	4.4		
		Okanogan	39,564	7.5		
		Pacific	20,984	22.5		
		Pend Orielle	11,732	8.4		
		Skamania	9,872	6		
		Stevens	40,066	16.2		
		Wahkiakum	3,824	14.5		
		Whitman	40,740	18.9		
Wisconsin	5,363,675	Ashland	16,341	16	3.50%	
		Bayfield	15,480	10		
		Buffalo	14,329	20		
		Burnett	15,116	17		
		Florence	5,107	10		
		Forest	9,698	9		
		Iron	6,252	8		
		Jackson	17,994	18		
		Menominee	5,088	14		
		Price	15,465	12		
		Rusk	15,030	16		
		Sawyer	16,344	12		
		Taylor	19,266	20		
		Washburn	16,020	19		
West Virginia	1,808,344	Pendleton	8,196	11.7	4.15%	4.10%
		Pocahontas	9,131	9.7		
		Tucker	7,321	17.5		
		Webster	9,719	17.5		
Wyoming	493,782	Albany	32,014	7.5	73.90%	91.00%
		Big Horn	11,461	3.7		
		Campbell	33,698	7		
		Carbon	15,639	2		
		Converse	12,052	2.8		
		Crook	5,887	2.1		



State	State Population	Frontier Counties	Population	Population Density	% of Pop. In Frontier	% of Frontier Counties
Wyoming, cont.	Fremont	35,804	3.9			
		Goshen	12,538	5.6		
		Hot Springs	4,882	2.4		
		Johnson	7,075	1.7		
		Lincoln	14,573	3.6		
		Niobrara	2,407	0.9		
		Park	35,786	3.7		
		Platte	8,807	4.2		
		Sheridan	26,560	10.5		
		Sublette	5,920	1.2		
		Sweetwater	37,613	3.6		
		Teton	18,251	4.6		
		Uinta	19,742	9.5		
		Washakie	8,289	3.7		
		Weston	6,644	2.8		
		Total	**81,610,635,475**			

Source: The Frontier Education Center, Albuquerque, NM

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix E:

National Pharmacy Purveyors HospiScript and Hospice Pharmacia

Appendix E: National Pharmacy Purveyors HospiScript and Hospice Pharmacia

Note: *NHPCO does not promote or endorse any vendor of services to hospices and palliative care organizations or other company. We are including information such as the following company descriptions to provide the reader with as many references as possible in order to help inform providers on choices.*

HospiScript

HospiScript Services is a pharmacy benefit administration company that focuses exclusively on the hospice community. Its mission is to help hospices understand and control their medication costs, freeing their resources for additional staff and improved patient care.

HospiScript works with approximately 300 hospices across the country, providing deep drug discounts in its network of 58,000 pharmacies. Clients receive a listing of pharmacies that serve their rural communities, including a full list of delivery, compounding and other pharmacy services available. Hospices also receive one consolidated invoice for their medications, regular reports that detail where costs can be controlled, and a partnership with an interdisciplinary team dedicated to outstanding service.

HospiScript understands that patient emergencies can be especially challenging in rural areas. The Comfort Care Kits are symptom management kits sent directly to the patient's residence. They are designed to provide patient and family comfort, reduce emergency medication and delivery needs, limit unnecessary hospitalizations, and improve symptom management. The Comfort Care Kits address pain, shortness of breath, nausea, vomiting, fever, agitation, restlessness, secretions, and respiratory congestion.

HospiScript understand that each hospice is as unique as the community it serves. They adopt a flexible approach that is catered to the way the hospice already works.

HospiScript clients receive:

- Reduced drug prices *from your local pharmacies*
- One consolidated invoice
- Custom drug plans
- Pharmacist and RN consultation
- 24-hour dedicated service and support
- Detailed drug use reports
- Educational resources

For more information, please contact HospiScript toll-free at 866/970-7500.

Appendix E: National Pharmacy Purveyors HospiScript and Hospice Pharmacia

Hospice Pharmacia

Hospice Pharmacia (HP), a division of excelleRx is a national medication management company serving end-of-life and chronic care patient populations. It provides fully integrated pharmaceutical care offerings that include pharmacotherapy care planning, clinical outcomes analysis and medication authorization and distribution, all supported by its proprietary technology platform. The foundation of this comprehensive offering is its Prospective Medication Therapy Management system, which shifts the medication selection process from traditional preference-based decisions to prescription recommendations based on empirical evidence and interpreted by approximately 150 of HP's experienced pharmacists specially trained in palliative and chronic care.

Prospective Medication Management

Although all medications may be effective, not all are *appropriate*. Hospice Pharmacia was founded on the belief that outcomes-driven medication management is the best approach to palliating patients' end-of-life symptoms.

HP produces optimal outcomes for the patient, the caregivers and the hospice. It monitors therapeutic outcomes to minimize common medication problems and to ensure that patients are taking the most appropriate medications that provide them with the best quality of life.

HP has actualized Prospective Medication Management (PMM) to target each of hospice's three primary areas of concern: quality, access and cost. PMM is used in all aspects of patient care, beginning with an assessment prior to the prescribing process.

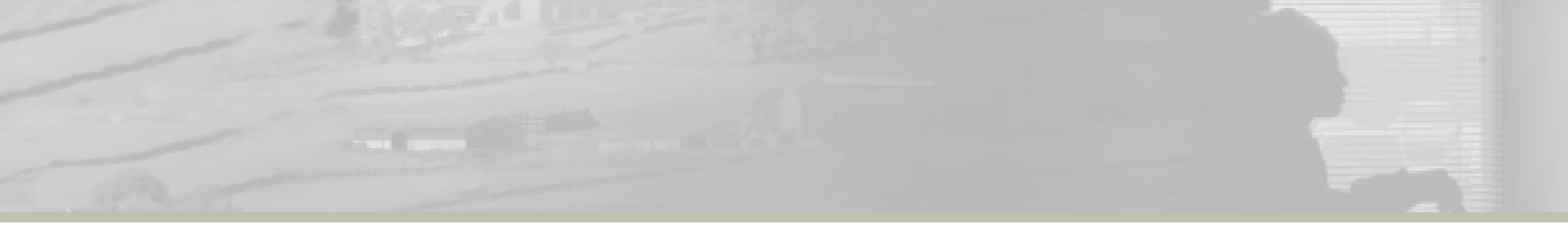
The Care Continuum

HP's Comprehensive Pharmaceutical Care Services enable access to appropriate medications for hospice patients. Palliative care trained clinical pharmacists and hospice nurses together perform medication care planning for each patient, then plan for medication delivery. Evidence-based proactive planning for symptom management is the mainstay of this pharmaceutical care strategy.

The HP Medication Use Guidelines (MUGs): The MUGs include nearly 50 evidence-based protocols that are peer reviewed and annually updated. These MUGs are the most comprehensive symptom management tool in the hospice industry.

The HP ComfortPak: The HP ComfortPak is an emergency kit that targets the most common symptoms experienced at the end of life. The ComfortPak minimizes time to palliation of new symptoms and reduces the risk of last-minute hospitalizations.

Xeris: Xeris is a data management system that simplifies and streamlines the patient medication management process for nurses, physicians, and pharmacists. This one tool encompasses all medication-related hospice functions, and is HP's way of sharing knowledge among practitioners to yield optimal patient outcomes.



Community Pharmacy Network: The HPRxCard allows for immediate access to medication through over 60,000 participating community-based pharmacies.

Aligned Incentives: HP helps overcome the challenge of managing hospice costs by aligning incentives and sharing economic risks. Pharmaceutical care services are offered at a per diem rate. The benefits of a per diem model include:

- Incentive for HP to assure that symptoms are managed;
- Disincentive to 'fill and bill' for medications;
- Ongoing monitoring of per diem parameters to assure that the per diem is a win/win; and
- Single bill that is easy to understand.

HP Partners always know what services are being provided for their patients, and at what cost.

Partnership Excellence

Hospice Pharmacia believes that success requires thorough on-going communication with its partners.

HP has a dedicated Performance Improvement Team responsible for operational enhancements and event resolution. Internal performance improvement goals pertain to operations benchmarks and service levels, which are monitored daily. External performance goals, which often target enhancements to and augmentation of services, are based on results of hospice partner satisfaction surveys and general idea exchanges.

HP employs a Relationship Partnering Team that focuses solely on enhancing relationships with partnering hospices. This team is committed to ensuring that hospice partners understand how to utilize all of the resources available to them through HP. This team provides hospice executives with a single point of contact.

Communication efforts also include:

- Newsletters with updates about the latest improvements to service;
- Hospice-specific accredited continuing education programs for nurses; and
- Monthly orientation and training sessions to refresh current hospice staff about HP services, and to orient new staff to the HP system.

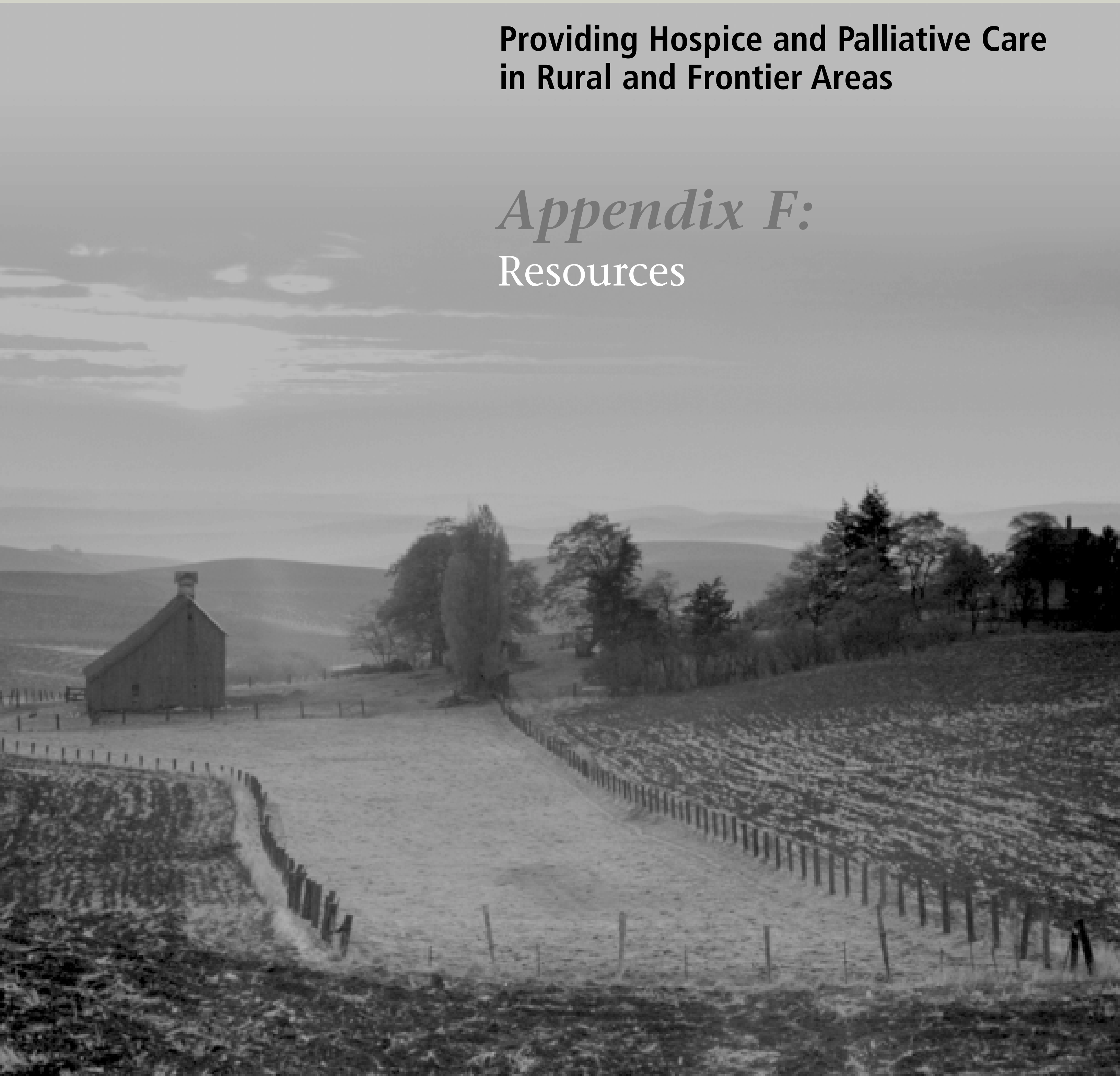
For more information, please contact Hospice Pharmacia toll-free at 877/882-7820.

CENTER TO ADVANCE PALLIATIVE CARE
National Hospice and Palliative Care Organization
NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix F:

Resources



Appendix F: Resources

Chapter 1: Introduction

Chapter 2: Definitions

List of Frontier Counties, from Frontier Education Center, HCR 65 Box 126, Ojo Sarco NM 87521, 505/820-6732, http://www.frontierus.org/index.htm?p=2&pid=6003&spid=6019 ***(or see Appendix D in this manual)***.

Chapter 3: Needs Assessment

Please see attachments on pages 146-169.

Needs Assessment Professional Literature

Altschuld, JW, Witkin, BR. *From Needs Assessment to Action*. Thousand Oaks, CA: Sage, 2000.

Witkin, BR, Altschuld, JW. *Planning and Conducting Needs Assessments*. Thousand Oaks, CA: Sage, 1995.

McKenzie, JF, Smeltzer, JL. *Planning, Implementing and Evaluating Health Promotion Programs*. Boston: Allyn & Bacon, 2001.

Chapter 4: Creating Capacity

DeCourtney, C, Jones, K, Merriman, M, Heavener, N, Branch, K. Establishing a culturally sensitive palliative care program in rural Alaska Native American communities. *Journal of Palliative Medicine*, 6 (3): 2003.

Alaska Native Tribal Health Consortium. *Alaska Natives and Cancer*. June 2004.

Virnig, BA, Moscovice, IS, Durham, SB, Casey, M. Do rural elders have limited access to Medicare hospice services? JAGS, 52: 731-735, 2004.

Chapter 5: Getting the Word Out

Commonly held misconceptions about hospice care: *www.capc.org*.

Six frequently asked questions about hospice care: *www.nhpco.org*.

Myths about dying: *www.hospicefoundation.org*.

Chapter 6: Creative Integration

Chapter 7: Financing

Chapter 8: Staffing

Chapter 9: Volunteers

The NHPCO manual, *Overview of Managing a Volunteer Program*, is available through NHPCO Marketplace. Go to: *www.nhpco.org* and click on "Marketplace" or call 800/646-6460.

Education and training resources from The Hospice Institute of the Florida Suncoast (*http://www.thehospice.org/inst.htm*) include *Hospice Patient/Family Volunteer Orientation Training Package* (hard copy and CD) and *The Volunteer Coordinator Guideline Manual* (hard copy).

For information on Faith in Action, a program of the Robert Wood Johnson Foundation, see: *http://www.fiavolunteers.org*/.

Chapter 10: Technology

Kinsella, A., *Telehospice: A Resource Manual for Program Development*. Available through the NHPCO Marketplace. Go to: *www.nhpco.org* and click on "Marketplace" or call 800/646-6460.

University of California-Davis rural project funded by Promoting Excellence in End-of-Life Care: *http://www.promotingexcellence.org/navigate/grantees.html*.

Chapter 11: Special Area Considerations

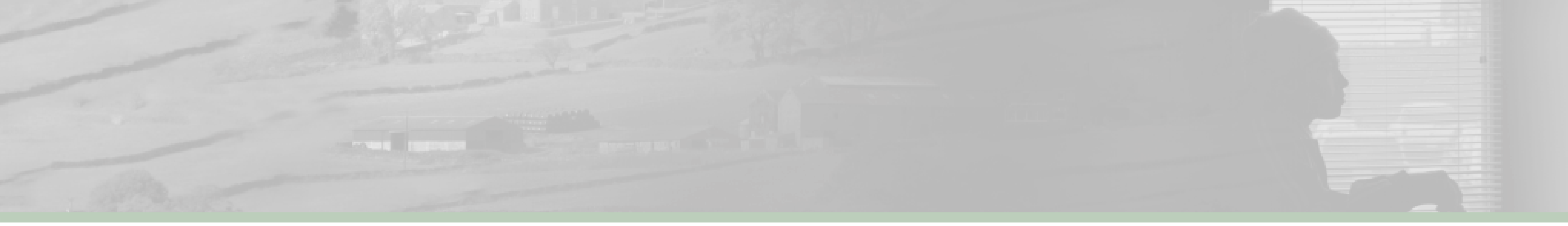
Chapter 12: Quality and How to Assure It

Family Evaluation of Hospice Care, a family satisfaction survey sent to hospice families by a hospice. Data are then submitted to NHPCO on a quarterly basis and participating hospices can then benchmark themselves against other hospices in the country. More information is available at *www.nhpco.org* in the Statistics and Research section.

NHPCO Standards of Practice for Hospice Programs, National Hospice and Palliative Care Organization, Alexandria, VA: *www.nhpco.org*.

Clinical Practice Guidelines for Quality Palliative Care, Bibliography. National Consensus Project for Quality Palliative Care: *www.nationalconsensusproject.org*.

Chapter 13: A Policy Discussion



Other:

General Resources on Hospice and Palliative Care

National Hospice and Palliative Care Organization (NHPCO)
1700 Diagonal Road, Suite 625
Alexandria, VA 22315
(703) 837-1500
www.nhpco.org

NHPCO offers its members access to research, legislative advocacy, and regulatory advocacy. Members stay informed on current innovations and news with NHPCO communications like *Newsline, e-Newsbriefs* and NHPCO's official journal, *Journal of Pain and Symptom Management*. NHPCO is the leader in end-of-life care education, offering the most comprehensive end-of-life care educational events in the country. Other membership features include NHPCO Insurance, NHPCO's Marketplace, referrals, technical assistance and much more. Visit *www.nhpco.org* for more information on NHPCO membership.

NHPCO's brochure, *Hospice Care and the Medicare Hospice Benefi*t, is available by calling NHPCO's Helpline 800/658-8898.

The Center to Advance Palliative Care (CAPC)
The Center to Advance Palliative Care (CAPC) is a national project sponsored by the Robert Wood Johnson Foundation and housed at the Mt. Sinai School of Medicine in New York, NY. CAPC's mission is to increase the availability of quality palliative care services for people with life-threatening illnesses, their families and caregivers. CAPC offers providers the tools and technical assistance they need to start and sustain palliative care programs. Services include: (a) educational conferences on palliative care program planning; (b) six palliative care leadership centers offering expert assistance to teams of physicians, nurses, administrators and financial or other staff working to build palliative care programs; and (c) through its website (*www.capc.org*), staff and consultants provides information and assistance to hospitals, hospices, clinicians, policymakers, payers and researchers seeking to improve the care provided to Americans with advanced illness.

Beresford, L, Mahoney, J, Michal, M. *One Patient, One Day: Making Your Hospice a Leader in End-of-Life Care*. Order from Summit Business Group, LLC, P.O. Box 130, Penfield, NY 14526, 800/689-6747.

Other Web links:

- Center for Medicare and Medicaid Services: *www.cms.hhs.gov*
- Federal Communications Commission: *www.fcc.gov*
- Frontier Education Center: *www.frontierus.org*
- National Rural Health Association: *www.nrharural.org*
- Medicare Payment Advisory Commission: *www.medpac.gov*
- Rural report: *http://www.medpac.gov/publications%5Ccongressional_reports%5CJune04_AppB.pdf*
- Hospice reports:
  - *www.medpac.gov/publications/congressional_reports/may2002_HospiceAccess.pdf*
  - *www.medpac.gov/publications%5Cother_reports%5C071304_PPS5_Hospice.pdf*

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Appendix G:
List of Attachments

Appendix G: List of Attachments

PHYSICIAN REIMBURSEMENT — HOSPICE

The following chart illustrates how physician reimbursement occurs, depending on the relationship of the physician to the hospice program.

Type of Physician	Type of Service	Source of Reimbursement	Rate of Reimbursement	Who Bills	Applied Toward Cap
Attending, Non-employee	Professional	Medicare Part B	80%/20%	Physician bills Medicare B Carrier	No
Attending, Non-employee	Technical Rate	Hospice Daily with Physician	Negotiated the Hospice	Physician bills	Yes, through daily rate
Attending, Non-employee	Administrative	Medicare Part B	80%/20%	Physician bills Medicare B Carrier	No
Attending, Employee	Professional	Medicare A FI	100%	Physician bills the Hospice	Yes
Attending, Employee	Technical	Hospice Daily Rate	Negotiated with Physician	Physician bills the Hospice	Yes, through daily rate
Attending, Employee (Medical Director)	Administrative	Hospice Daily Rate	Negotiated with Physician	Physician bills the Hospice	Yes, through daily rate
Consulting	Professional	Medicare A FI	100%	Physician bills	Yes the Hospice
Consulting	Technical	Hospice Daily Rate	Negotiated with Physician	Physician bills the Hospice	Yes, through daily rate

Professional Services: Actual procedures and billable care plan oversight services performed by the physician as designated by the appropriate CPT-4 code. These include physician consultation, physician interpretation of an x-ray, CT scan, or MRI, or physician interpretation of a laboratory test.

Technical Services: Include lab, x-rays, and any other non-professional services performed by the physician or other health care professional.

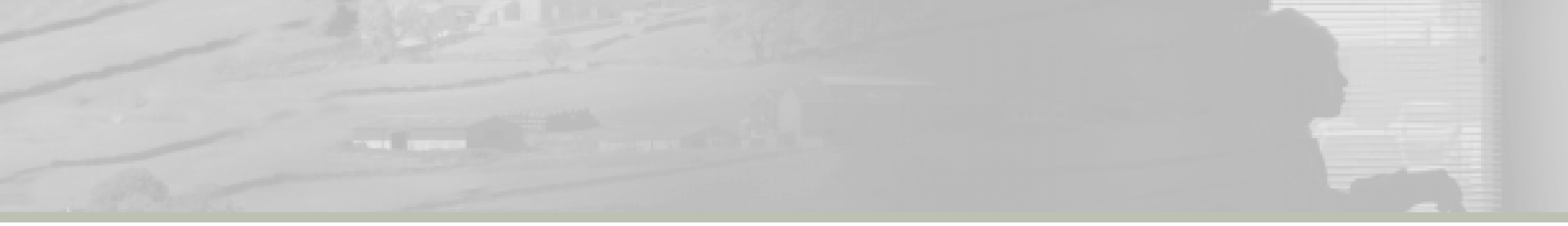
Administrative Services: Include participating in the establishment, review and updating of the plan of care, supervising care and services, and establishing governing policies (physician member of IDG).

Attending physician, non-employee: The patient designates the physician primarily responsible for his/her care during the election process.

Attending physician, employee: If the attending is an employee of the hospice or volunteers with the hospice (e.g., as medical director or physician member of the IDG), the physician's professional services are billed to Medicare Part A by the hospice.

Consulting Physician: Any physician services other than those rendered by the attending physician are classified as consulting physician services.

Source: Health Care Financing Administration, March 26, 1998, and 42 C.F.R. Section 418.304.



PLANNING AND GOAL SETTING INTERVIEW

Interviewee_______________________________________ Interviewer____________________________________

1. **Current Status**

   What is your understanding of the Hospice Program?

From your perspective, what are the strengths and weaknesses of the program?

2. **Wood River Valley Issues**

   Since Hospice is a provider of health care services for the Wood River Valley, what important issues do you think we will be facing?

   What considerations related to life in this valley need to be a part of our planning process?

   What emerging trends will be impacting Hospice?

3. **Future**

   If there were no limitations on our ability to accomplish any goal, what would be your vision for the Hospice program?

   What one thing would you say is most important for the program to accomplish within the upcoming year?

4. **Education**

   What information or programs do you think would be helpful to the community?

5. **Conclusion**

   Do you have any questions?

   Any other comments or ideas you would like to offer? Thank You!

Source: Hospice of the Wood River Valley, PO Box 4320, Ketchum, ID 83340, 208-726-8464

Appendix G: List of Attachments

COMMUNITY SURVEY

Hospice Care provides support to individuals and families at the end of life. Your answers to the following questions will assist us in understanding community members' needs related to care.

1) **Have you ever heard about Hospice Care Benefits available under the Medicare Health Insurance Program?**
☐ No *(If no, skip to question #2)* ☐ Yes ☐ Not sure

2) **How did you learn about Medicare Hospice Care Services**
☐ Personal experience with the program
☐ Professional experience with the program
☐ A health care provider informed me
☐ Brochures
☐ Newspaper, TV, radio
☐ Other: ___________________________________

3) **Which of the following services are covered under the Medicare Hospice Benefit?**

Please check all that apply
☐ Home Nursing Visits
☐ Home Health Aide Visits (help with personal care)
☐ Homemaking Services (light housekeeping, meal preparation)
☐ Respite Care at Home (care provider to allow time out for the regular caregiver)
☐ Respite Care in the Hospital
☐ Medical Social Services
☐ Pastoral Care
☐ Prescription coverage for medications for comfort care
☐ Hospital care for comfort and symptom management
☐ Medical equipment to use at home
☐ Volunteer support

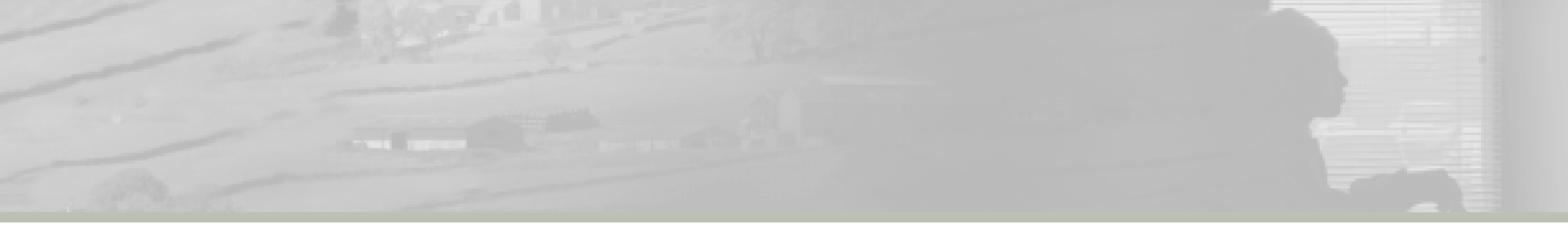
4) **Which of the following agencies are Medicare Certified Hospice Care providers?**
☐ North Country Home Health and Hospice
☐ Ammonoosuc Community Health Services
☐ Weeks Home Health Agency
☐ Hospice of the Littleton Area

5) **If you were in need of care due to a terminal condition, what would be most important to you?**

6) If you were caring for a loved one who was dying, what would be most important to you as a caregiver?

7) Would you be interested in participating in an interview to further help us in our study? If so, please note your name, address and telephone number? Thank you!

Source: North Country Home Health and Hospice, 536 Cottage Street, Littleton, NH 03561



COMMUNITY HEALTH CARE PROVIDER INTERVIEW

1) What do you feel are the most beneficial aspects of the NCHHA Hospice Program?

2) What areas do you see as needing improvement?

3) What suggestions might you share to improve the program?

4) Would you be interested in being involved in an interdisciplinary coalition focusing on end of life care?

<u>Follow up interview tool for community respondents</u>*:*

1) What are your primary concerns related to end of life care for yourself?

2) What would you be most concerned about as a family member caring for a loved one at the end of life?

3) What qualities and criteria would you value most in choosing a Hospice provider for yourself or a loved one?

4) How would you feel about using our volunteers to help with the Hospice care?

Source: North Country Home Health and Hospice, 536 Cottage Street, Littleton, NH 03561

IN THE EVENT OF AN UNEXPECTED VACANCY OF THE EXECUTIVE DIRECTOR

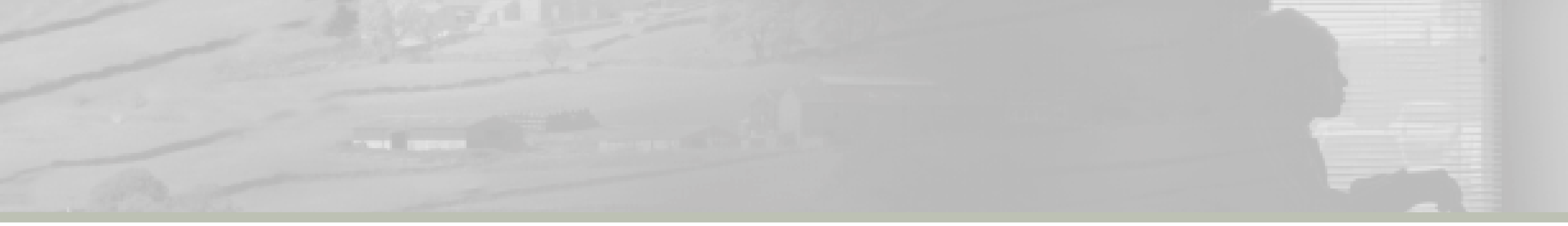
(A transitional plan would be used for a planned retirement or change)

1. **The President or next-in-line officer would call a meeting at the office of the Executive Committee or the entire Board and activate the "plan" after review of the organizational status at the time.**
   a. Ask the office manager to prepare a list of current plans and activities (current census, groups in progress, camp plans, volunteer trainings).
   b. Develop a plan to insure stability of the organization and quality patient care/services.
   c. Create a public statement that can be communicated to all, consistently.
   d. Arrange to have people in the office to answer phones and keep a calm atmosphere.
2. **Delegate the following areas of responsibility and designate staff in charge:**
   a. Patient Care (Hospice patients, sudden deaths, walk-ins) – allow RNs to decide on their own schedule, including "on call" that works for them to maintain quality of care. Volunteer RNs can be called on to assist if needed.
   b. Groups — assign a staff person to assess each group. Does it need to continue, can it be postponed or suspended? Set priorities.
   c. Volunteers — have the person that knows the volunteers best, their strengths and schedules; work with RN input to assign/match with patients.
   d. Events and Other (depending on the time the vacancy occurs)
      i. Memorial Tree — assign someone to manage, following the process and timeline in the Memorial Tree folder.
      ii. Annual Report — a Board member can do a letter to explain the vacancy; do the best you can do regarding accomplishments and finances; obtain donor list from office manager. Explain specific data is not a priority, that the organization is focusing its attention on patient care and services to the community.
      iii. Annual Funding Letter — a Board member can write the letter of appeal (previous letters can be used as an example). Office manager can manage the mailing, printing, and organize volunteers to assist.
      iv. Volunteer Recognition — Board can do with the help of the other staff. Prepare a list of involved volunteers and the Board can decide on the appropriate event.
      v. Community Presentations — decide on who will make the presentation, depending on the subject, evaluate the priority at the time or decline/postpone.
      vi. Critical Incident Stress Debriefing (CISD) – there would be no trained staff at this time to perform this function. Other community resources would need to be asked or a neighboring community would need to be called.
3. **General Management**
   a. The President or Treasurer would need to sign checks, watch the budget, and authorize expenses on a weekly basis.
   b. There is a weekly staff meeting on Monday mornings A Board member may wish to attend to stay current with day-to-day activities at that time.
   c. It would be important for Board members to support staff on a regular basis and to be sensitive to their ability to work together in new ways.
4. **Questions?**

   Would you want to send a letter to the community to reassure (MDs, hospitals, etc) or have a media release? It would seem that the circumstances and the level of apprehension within the community would determine appropriate action. The Professional Advisory Committee may be helpful in this decision.

Note: Hospice of the Wood River Valley is located in a small, rural area in central Idaho, populated with 19,000 residents. HWRV is the sole provider of hospice/palliative care in this area. The current staff is 2.9 FTEs. This document reflects our hospice's plan, understanding that people wear several hats and the importance of sustaining the services with a staff reduced to 1.8 FTE's. The policy is designed to maintain services and provide reassurance to the community that is heavily reliant on HWRV for all services related to death, dying, grief and loss. Our own document actually identifies specific personnel to take certain responsibilities and the document is updated regularly to coincide with programs and staff.

Source: Hospice of the Wood River Valley, PO Box 4320, Ketchum, ID 83340, 208-726-8464



EXECUTIVE DIRECTOR SEARCH

(Companion piece to “In the Event of an Unexpected Vacancy of the Executive Director”)

1. **Call a meeting and decide if there will be a Search Committee or if the Board will do this work. There are professional search firms.**
2. **The Board should first develop a priority list of what they want in a new E.D. and also who else they want to provide input to insure responsiveness to and participation from the community.**
   a. Staff
   b. Volunteers
   c. The hospital and skilled nursing facility
   d. Large donors
   e. Community leaders
3. **Develop the final criteria of what of what you are looking for…for example**
   a. Believes in and values our model of care
   b. Clinical competencies
   c. Leadership qualities (integrity, motivational, etc.)
   d. Management skills (financial, personnel, planning)
   e. Community expertise (donor development, relationships)
4. **Review and revise job description.**
5. **Decide on a salary range and budget for the Search (transportation, lodging, etc.).**
6. **Advertise (locally, Idaho State Hospice Organization, NHPCO).**

   There is an expectation of excellence in this community and the person needs to be strong and competent to succeed. Recruit for success.

   Look for background/experience that includes:
   - Hospice experience that is transferable to this model
   - Program development and wide scope of services
   - Not-for-profit management
   - Working with a Board of Directors
   - Volunteer management, recruitment, retention, supervision, training
   - Fund development, donor relations, grant writing
   - Community skills, collaborative alliances, etc.
7. **Review applicant resumes according to criteria**
8. **Develop a packet to send to candidates you are going to interview (send letter to all applicants acknowledging their interest).**
   a. Packet contents to familiarize applicant with HWRV
      i. Profile of organization
      ii. Area served and nature of the jurisdiction
      iii. Population, geography, weather, attractions
      iv. Annual Report
      v. Program statistics
      vi. Staff size and volunteer involvement
      vii. Budget and financial reports
      viii. Most recent issues of local papers
      ix. Sun Valley Guide or Sun Valley Magazine

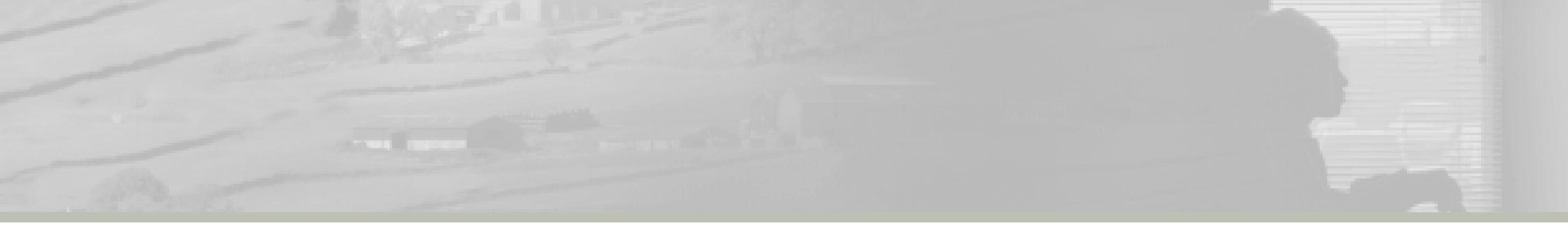
EXECUTIVE DIRECTOR SEARCH, cont.

9. **Invite candidate to come for an interview, offer to assist with lodging, perhaps prepare a "Welcome Basket" of local items, have someone meet them at the airport, if necessary…in other words, make them feel welcome and comfortable.**
10. **Interview finalists with an objective grid or tool based on desired competencies.**
    a. Have prepared questions and assign to persons involved in the interview.
    b. Ask key staff if the have questions they want to have answered and/or have them present for clinical evaluation.
    c. Have the candidate meet staff, maybe over lunch.
    d. Tour community (hospital, general layout, housing options).
11. **Make the offer.**
12. **Offer to help with housing, realtors, etc.**
13. **Plan for orientation — ask candidate how they would like to be introduced to the community and to their new position.**
    a. Meet staff with coffee; let them explain their background, initial thoughts.
    b. Orientation plan to include:
        i. Current patients and activates
        ii. Read charts, explore office, ask questions
        iii. Read Board minutes/policies
        iv. Intro to computer — meet with office manager
        v. Fill out W-2 forms, sign confidentiality statement
        vi. Read personnel policies
        vii. Tour hospital, SNF
        viii. Joint visits to patients
        ix. Introduce to banks, others with whom we interact regularly

14. **Have Open House to meet people? Article in paper?**

These are general guidelines to be revised/modified at the time. The document is a starting point/outline that can be used to begin a process.

Source: Hospice of the Wood River Valley, PO Box 4320, Ketchum, ID 83340, 208-726-8464



NEW BOARD ORIENTATION OUTLINE

History:

Mission Statement

Hospice philosophy, volunteer model of care, Medicare model of care

Overview of current services, service area

Review of most recent Annual Report

Program statistics with explanation and comparison to national statistics

Current programs, groups and plans

Patient chart (admission criteria, consents, proves, referrals, etc)

Volunteers (recruitments, training, retention, recognition, background checks, insurance, etc.)

Major assets/challenges facing the organization

Financial/Staffing:

Budget — balance sheet — budget report — investments — board packets

Policies re: investments, cash management, benefits, etc.

Agreements: Local pharmacies, hospital, nursing home, residential care

Fundraising: Annual fundraising letter, Memorial Tree, fundraising expectations and involvement

Staffing/Benefits: Personnel, IRAs, health care, education, retirement

Governance:

Board of Directors, Professional Advisory Committee, consumer, volunteer

Directors & Officers Insurance and other insurance policies

Board history, composition and representation

Meetings, retreats, current organizational goals

Responsibilities of members — attendance policy, fundraising, expectations & involvement

Confidentiality/Conflict of Interest — sign statements

National/state/community involvement (hospice and other):

Memberships and participation

Resources and recommended reading:

Power Steering: A Guide for People on Boards, by Charles Ewell, PhD

The Board Members Book, by Brian O'Connell

Source: Hospice of the Wood River Valley, PO Box 4320, Ketchum, ID 83340, 208-726-8464

MISSION

The Littleton Regional Hospital (LRH) Palliative Care Team (PCT) is a multidisciplinary team of health care professionals who provide holistic services to patients who have advanced incurable illness. We help patients identify their individual goals for the latter stages of their life and align their medical care with those goals. Our goal is to improve the quality of life of our patients by relieving pain and managing symptoms, thereby helping patients ultimately die with dignity.

Objectives

1. Write a "standard of care" for each subspecialty/department to be used to direct services for identified palliative care patients
2. Write appropriate policies, procedures, and/or standing orders for each subspecialty pertaining to palliative care services
3. Assemble a clinical team to provide palliative services to identified patients at LRH
4. Educate staff in each department about palliative care and standards of care defined by the PCT

The mission will be accomplished by:

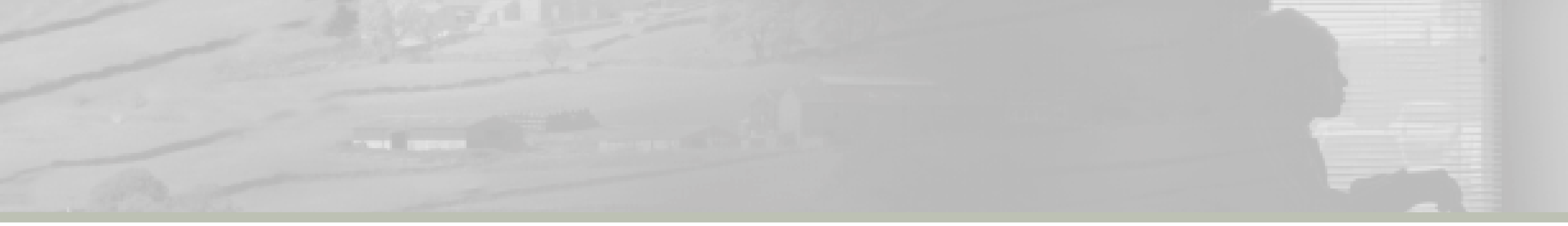
- a) dissemination of the philosophy and practice standards of palliative care by team members to each department and throughout the hospital and community both informally and in the process of patient care
- b) formal educational endeavors by team members
- c) formal consultation for appropriate inpatients
- d) supporting and linking with community agencies and providers to improve communication and teamwork and improve quality of palliative care throughout the community
- e) support a community based palliative care coalition

Process

1. Identify interested and motivated representatives of each subspecialty area with the core team to include:
    - a. Medical
    - b. Nursing
    - c. Psychology/ Counseling
    - d. Social Work
    - e. Pharmacy
    - f. Nutrition
    - g. Spirituality/ Pastoral Care
    - h. Discharge Planning
    - i. Home Health Care and Hospice Programs
    - j. Community Volunteers/ Hospice of Littleton Area

Supporting team members would include:

- a. Pain/anesthesia specialists
- b. Physical, Occupational, and Respiratory Therapy
- c. Funeral Homes
- d. Community complementary health caregivers
- e. Community psychology providers
- f. Administration/ Billing
- g. Ambulance services/Prehospital Care
- h. Cardiac and Diabetic Counseling/Rehab



MISSION, cont.

2. Representatives of each subspecialty area will develop “standards of care” to help direct services pertaining to LRH patients in that area.
    a. these should be simple and useful documents focused on basic goals of care and methods to achieve these goals
    b. common software (MS Word) should be used
    c. these will be collated in a web-based document
    d. all members of the team will have opportunity for input and revision
3. “Standards of Care” will be used to develop policies, procedures, and/or standing orders as appropriate, including:
    a. A LRH specific palliative care intake form
    b. Physician based standing orders for pain and symptom management
        i. Narcotic guidelines/ standing orders
        ii. Comfort care orders
    c. Nursing protocols for palliative patients
    d. Subspecialty based standards as indicated
    e. Review of present hospital based guidelines and procedures for pain management, routine bowel orders, skin care, nausea and vomiting, and other symptom management
        i. Edit and improve documents to support evidence based and systematic assessment and management of symptoms
4. A clinical team led by nursing intake will be developed for palliative care patient evaluations. Intake will be based on an “intake form” and completed by an active nurse of the PCT. Intake will identify specific goals and areas of need for that individual patient and appropriate specialists will be gathered to review the case based on those needs. Interdisciplinary team meetings will be a venue for discussion of palliative care patients.
    a. The primary physician (referring physician) can request or not request physician involvement from the palliative care physician as needed
        i. Intake will occur as quickly as possible but at longest within 18 hours during the week and 36 hours on the weekend/holiday
        ii. Case review and meetings will be completed by all available members within 36 hours during the week and 72 hours on the weekend.
        iii. A consultative report collated by the intake caregiver and/or physician including reports from each specialty will be dictated or written within 48 hours during the week
        iv. A follow up assessment by the intake caregiver will occur at the time of discharge and at minimum a phone follow up 1-2 weeks after discharge to review goals
        v. A brief satisfaction survey will be administered prior to and after evaluation
        vi. Service is provided to the referring physician and the team acts only for that physician. The team does not take over care and does not write orders unless specifically asked for by the consulting physician.
5. Outpatient assessment and management will be considered once the inpatient program is stable and running well

Source: Littleton Regional Hospital Palliative Care Team, Littleton Regional Hospital, Littleton, NH 03561

PHYSICIAN AND PALLIATIVE CARE TEAM STANDARDS OF CARE FOR PALLIATIVE CARE

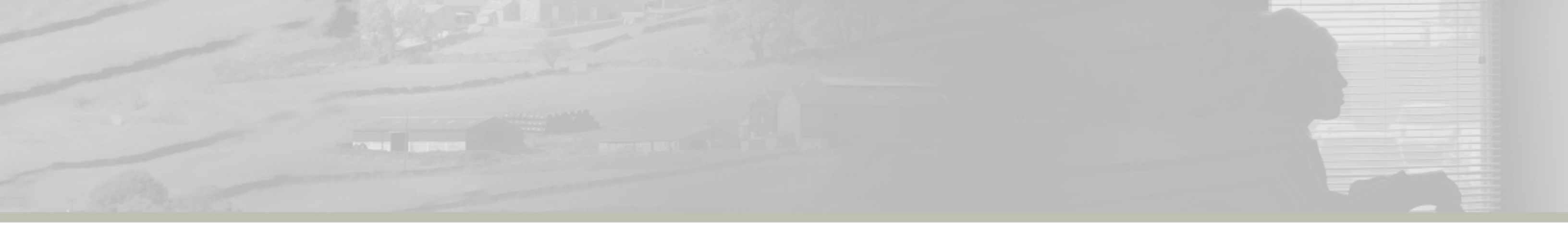
Standard

A. **Medical consultation will include a review and/or assessment of the patient's end-of-life goals. Recommendations will attempt to align medical care with personal goals:**
   1. Investigations or treatments that decrease qualify of life and are not in keeping with patient goals will be identified.
      a. Simple and cost-effective treatments will generally be preferred over complex or costly interventions assuming equivalent evidence for effectiveness.
   2. Symptoms that impair quality of life will be identified and recommendations for treatment will be aggressive and timely.

B. **Medical palliative care recommendations will focus on pain and symptom management and relief of suffering.**
   1. **All symptoms will be assessed to include:**
      a. Quantity
      b. Quality
      c. Impact on functioning
      d. Personalized attainable goals for each symptom

Process

A. Physician will be part of every palliative care consultation. The primary care or other referring physician can act in this role if they wish. Otherwise the on-call palliative care physician will consult. The consulting physician will:
   1. Review the intake record and reason for consultation with specific focus on the identified issues and goals on the final page.
   2. Do a complete review of recent and old records to include appropriate recent tests; other physician notes and consultations; and relevant surgeries or procedures.
   3. Complete a thorough history and physical examination including corollary history from appropriate relations (e.g., power of attorney for health care).
   4. Recommendations for laboratory, radiological and other investigations will be limited to those necessary or likely to help improve outcomes.
   5. Treatment recommendations will focus on a symptom-based approach that attempts to achieve relief of identified symptoms, addresses identified patient-specific issues and attempts to help attain identified patient-specific goals (per intake and physician history).



PHYSICIAN AND PALLIATIVE CARE TEAM STANDARDS OF CARE FOR PALLIATIVE CARE, cont.

B. Specific physician issues include:
  1. Pain control
  2. Nausea or vomiting
     a. All patients initiated on narcotics will have at least PRN anti-nauseates available and consideration for regular anti-nauseates for the first 2-3 days
  3. Constipation
     a. All patients who are on narcotics or are bedridden will have a bowel routine recommended
  4. Agitation /terminal agitation
  5. Excessive sedation
  6. Anxiety or depression
  7. Any other symptom felt appropriate for physician input by intake coordinator

C. Physician input into team meetings (without complete physician consultation) is appropriate for single or simple medical issues that are not primary issues for the patient as judged by the intake caregiver.

<u>Resources available:</u>

Bedside Pain Manager: laminated sheet at nursing station
- narcotic equivalences, dosing information, cost…
- options for adjuvant pain meds

Oxford Textbook of Palliative Medicine: large text at nursing station
- the accepted comprehensive and authoritative text on palliative care (2004 edition)

Evidence based pain and symptom management at the end of life: small reference text on nursing station
- evidence based interventions

Handbook of Palliative Care: small handbook at nursing station
- overview with basic and appropriate interventions for common conditions and situations

*Up-to-Date Articles: Patient evaluation in palliative care, Hospice: philosophy of care and appropriate utilization; Symptom control in the terminally ill cancer patient…*more available on computer in dictation area

Web Based Resources:

<u>www.albertapalliative.net</u>

<u>www.eperc.mcw.edu/login/start.cfm</u>

Source: Littleton Regional Hospital, Littleton, NH 03561

PHARMACY STANDARD OF CARE FOR PALLIATIVE CARE

Standard

The pharmacy will support palliative care initiatives. Support will focus on collaborative processes that improve the care of patients within the scope of the medical care goals established by the patient; their family and an organized palliative care team. An integral part of the health care team, pharmacy has a responsibility to influence care outcomes in a positive way by undertaking activities that ensure the optimal selection and dosage of medicines, their secure and efficient distribution, and their safe and effective administration.

Process

To participate as a member of the palliative care team.

To provide high quality pharmacy services to our palliative care patients.

To participate in patient-focused multidisciplinary team meetings and provide pharmaceutical advice within this forum.

To provide distributive services that ensure medication is available in a timely and cost-effective manner.

To maintain and develop pharmacy services focused on palliative care needs. These services may include but are not limited to the following:

Monitoring narcotic use:

- Review initial conversion of narcotic regimes within 24 hours of admission

By direct physician contact and/or the Interdisciplinary Team:

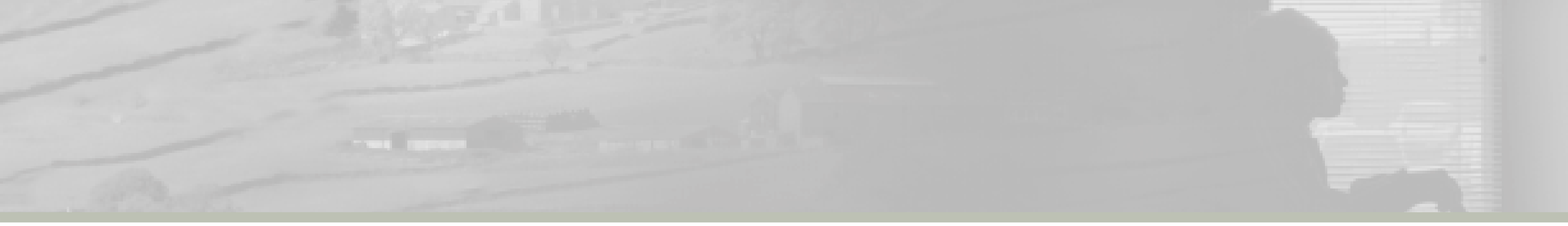
- Suggest / review dosing adjustments to maintenance rates
- Suggest / review dose adjustments for "breakthrough" pain
- Monitor effectiveness of pain control

Review medication utilization:

- Review all medication orders and rational for prescription
- Suggest alternatives, dose adjustments, new therapies or discontinuation
- During review, palliative care patients will be considered to have renal and hepatic impairment unless otherwise documented

Rev 12-16-03

Source: Littleton Regional Hospital, Littleton, NH 03561



PASTORAL CARE STANDARD OF CARE FOR PALLIATIVE CARE

Standard

For Palliative Care patients at LRH, Pastoral Care will provide spiritual and emotional support for those patients, their families and staff who work with them. A major aspect of this is to maximize the utilization of support systems already present.

Process

1. Assess the patient for pastoral needs during the intake assessment as provided in the Intake Assessment package.

2. The LRH Med/Surg staff will call the patient's Pastor, Priest, Rabbi or other person or spiritual resource designated by the patient within 24 hours of a patient's request.

3. LRH Pastoral Care available to palliative care patients and their families 24 hours a day, 7 days a week on an emergency or on-call basis.

4. The LRH Pastoral Care Coordinator will visit palliative care patients who request a visit within 36 hours of the patient's request (or 72 hours on the weekend) if the patient is still an inpatient at LRH.

Source: Littleton Regional Hospital, Littleton, NH 03561

RESPIRATORY STANDARD OF CARE FOR PALLIATIVE CARE

Standard

The goal of Palliative Care is Comfort Care. The diagnosis/condition is not reversible or curable. The patient outcome won't change, but the path can be made comfortable and dignified with our assistance. The entire health care team needs to realize along with the patient, when enough intervention is really enough, and when it's time for the next journey to begin.

Process

All palliative patients with abnormal evidence of work of breathing and evidence of discomfort associated with this should receive a respiratory consult including one of:

- abnormal respiratory rate, cyanosis
- Evidence of increased effort of breathing (accessory muscle use, in drawing, posturing for more air…)
- other evidence of difficulty breathing

+ one of:

- fear of loss of breath/breathing
- complaints or signs of discomfort or difficulty with breathing
- family concern about breathing problems

Observe, assess and treat the patient condition at the moment. The bottom line and goal is patient comfort, not monitors and numbers.

Respiratory Assessment

1. Identify patient dyspnea/work of breathing
   a. determine to what degree it is physiological and/or psychological/anxiety
2. Refrain from using pulse oximetry monitors as this increases anxiety levels of patient and family members

Treatments

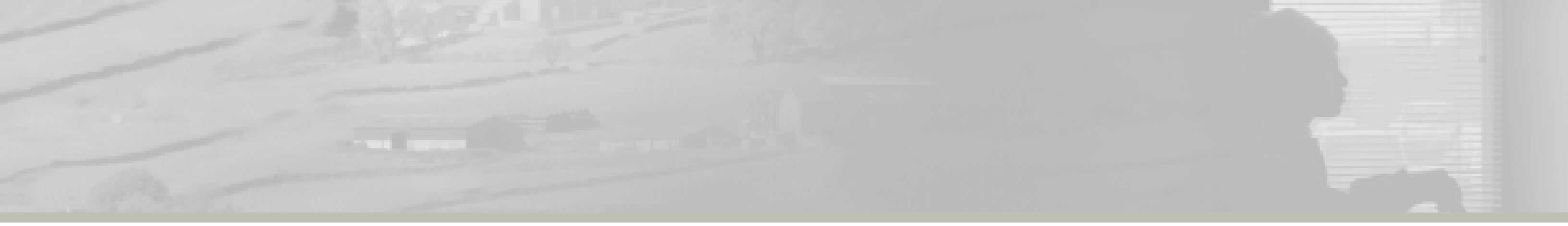
1. Directly address cause by positioning or medicating patient
2. Apply low flow oxygen therapy as appropriate
3. Explain use to the patient and family to decrease work of breathing
4. If necessary, adjust or increase FIO2 to a higher % of oxygen to improve patient comfort level
5. Staircase O2 delivery to higher liter flows to venturi masks and non-rebreathing masks, if necessary for patient comfort
6. Masks may also be used simultaneously with cannula if needed.
7. Updraft nebulizer treatments most often don't eliminate respiratory distress and can even increase HR and B/P and mobilize secretions that increase coughing spasms.
   - Exceptions include conditions with reversible active bronchospasm (asthma, COPD)
   - Nebulized morphine has anecdotal evidence of success but larger studies do not support frequent or standard use

Airway Secretions

Suctioning is uncomfortable and can cause hypoxia, increase dyspnea, stimulate gag reflex and anxiety levels. Frequent suctioning may be avoided with patient positioning and turning and with prescribed medication

- Suctioning should be performed only when needed. Use a yankaur/tonsil tip device for aspiration prevention and airway clearance
- Position the patient as high as possible to assist patient swallowing secretions and to minimize gagging and aspiration
- Suction catheters may help clear thinner secretions
- Scopolamine, glycopyrrolate, Hyosine or atropine are options to minimize secretions

Source: Littleton Regional Hospital, Littleton, NH 03561



This document is to be used as a guideline only. Each case should be evaluated and treated individually based upon clinical findings.

END-OF-LIFE STANDARD OF CARE/NURSING PLAN OF CARE

Effective:

Approved by:

Reviewed:

Revised:

Procedure: The following Standard of Care/Nursing Plan of Care will be implemented for patients who are (1) at an advanced stage of their illness and have a limited life expectancy, (2) hospice patients needing pain management or respite, or (3) Medicare Hospice patients utilizing the respite benefit. The physician will not need to write out individual orders to this effect. The Standard of Care/Nursing Plan of Care will delineate the care to be provided. A copy of this Standard of Care is present in the pharmacy to aid in drug supply/delivery.

Treatments/Interventions/Assessments:

1. Clarify goals of palliative care for advanced disease (PCAD) with patient and/or family
2. Facilitate discussion and documentation of advance directives
3. Initiate physician order sheet/review daily
4. Comfort assessment to include: pain and symptom management needs, psychosocial coping, anticipatory grieving, and social/cultural needs, spiritual issues and distress
5. VS — None unless useful in promoting patient/family comfort
6. Assess for and provide environment conducive to meet patient and family needs

Pain Management:

1. Diet: Selective diet with no restrictions. Nutrition to be guided by patient's choice of time, place, quantities and types of food desired. Family may provide food
2. Educate family in nutritional needs of dying patient
3. IVs for symptom management only
4. Transfusions for symptom relief only
5. Intake and output, consider goals of care relative to patient comfort
6. Weights, none unless useful in promoting patient/family comfort

Activity:

1. Activity determined by patient's preferences and ability. Patient determines participation in ADLs, (i.e., turning and positioning, bathing, transfers)

Psychosocial Needs:

1. Psychosocial comfort assessment of patient, primary caregiver, grieving process of patient & family
2. Psychosocial support: Offer emotional support, support verbalization and anticipatory grieving, encourage family caring activities as appropriate/individualized to family situation and culture and facilitate verbal and tactile communication. Assist family with nutrition, transportation, childcare, financial, and funeral issues
3. Assess bereavement needs
4. Refer to Hospice

Spiritual Needs:

1. Spiritual comfort assessment, spiritual supports, needs and/or distress
2. Refer to Chaplain

Tests/Procedures:

1. Usually unnecessary for patient/family comfort (all lab work and diagnostic work is discouraged)

Consults:

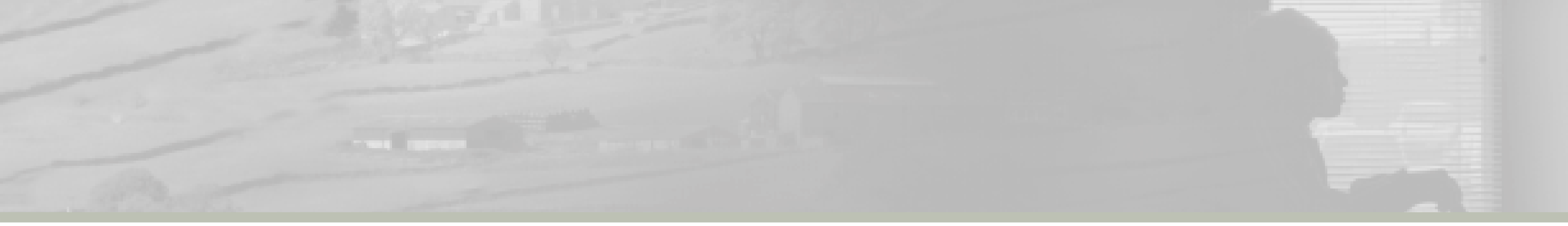
1. Initiate referrals to institutional specialist to optimize comfort and enhance Quality of Life (QOL) only

Source: Littleton Regional Hospital, Littleton, NH 03561

INTAKE NURSE PROCESS

1. A consultation occurs and is communicated by the clerk or the referring source to the palliative care intake nurse on call.
2. Intake occurs as soon as appropriately possible but within 18 hours during the week and 36 hours during the weekend.
3. The intake nurse meets with the patient and appropriate family members to discuss what a palliative care consultation means including:
    a. Introduction of who you are.
    b. That you have been asked to come in by the referring doctor.
    c. That you are there to help the patient identify their goals for medical treatment and how we can best fulfill those goals.
    d. That we are generally asked to help patients who have serious medical conditions that are not curable.
    e. That our expertise is in treatment of symptoms and improving quality of life in a holistic manner.
    f. That we are consultants and will give our recommendations to the referring/primary physician and that we will not manage their condition or take over their care.
    g. That the patient and their personal doctor will choose what to do based on what we recommend.
4. An intake form is completed including relevant sections from the nursing sheet.
5. The intake form is placed in the chart with the physician consultation forms in the front section.
6. Appropriate team members are called immediately after the form has been completed. Team members are notified that the case will be discussed the next day at the IDT meeting and are urged to attend if possible. Team members complete their consultation in appropriate time frames.
7. The intake nurse attends the IDT after consultation to review the case with other clinicians.
8. The intake nurse communicates personally with the primary physician that the consultation has been completed and has what it has included and briefly reviews recommendations with the primary referring physician.
9. The intake nurse dictates or writes a final consultation note to the primary referring physician that includes:
    a. Reason for consultation
    b. Identified goals of the patient and family
    c. Identified medical issues
    d. A care plan to address each of these issues based on the team's recommendation and gleaned from the IDT meeting, the physician and other team members' consultation reports and other pertinent information attained
    e. This dictated note is placed in the chart in the front section and replaces the intake form which is moved to the nursing section of the chart

Source: Littleton Regional Hospital, Littleton, NH 03561



WORKSHEET FOR NURSE INPATIENT INTAKE

Notes:

- **Obtain as much information from the chart as possible**
- **Focus on A-D and F-G. Complete review of Symptoms (ROS) as appropriate and able based on the patient's condition. Otherwise targeted ROS**
- **Customize the assessment to the patient's needs and wishes**

A) Introduction and Discussion of Role

a. "Hi, I am ____________, a palliative care nurse. I have been asked by Dr. ____________ to try to think of some ideas to help you feel better and to make sure you have access to all the help you need. Do you have any questions about my role?"
b. Explain role to support person in addition to present medical treatment
c. Identify any initial goals or wishes

B) *Adjustment to illness* (Use the BATHE technique)

a. "Tell me about your illness?" "What have your doctors told you about your illness?" Get the Background. Identify where the person sees them themselves in terms of their illness AND in their life in general
b. "How are you coping with this illness?"
c. "How is the illness Affecting you?" Name the emotion, Validate it.
d. "What Troubles you most about this illness?" "Tell me what frightens you most…."
e. "How are you Handling this?" Identify sources of support in past and present and sources of strength in self.
f. Show Empathy: "This must be very hard for you…"
g. "What do you think the future holds for you?"

C) Family Adjustment to Illness and Support Structures:

a. "Tell me about your family"
b. "Who are the most important people in your life?" "How are they adjusting to this illness?"
c. "What does your family think about all this?"
d. "What activities do you like to take part in?" Identify other supports as well as immediate family and their roles…

D) Ability to do ADL's : feeding, bathing/cleaning, dressing, transfers, mobility, continence

a. "What daily activities do you need help with?"

E) Review of Systems: Prioritize and cover what seems pertinent and possible depending on the patient's ability to communicate, energy level… This idea is to identify unrecognized issues and problems that may be addressed by the PCP or consulting physician, not to explore already identified and treated problem or search in precise detail.

a. "If we could help you feel better in one specific way, what would it be?"
b. Ability to understand and make decisions, delirium, disorientation, abnormal behaviors
c. Ability to afford and take medications as prescribed
d. Pain control (pain assessment tool if indicated: appendix #1)
e. Fatigue: rate severity, impact on daily function
f. Food and Nutrition/ Hydration: anorexia
i. Note any swallowing problems and interest in food
g. Bowels:
i. Note incontinence, special needs
h. Nausea/ Vomiting
i. Urine: incontinence, ability to control
j. Sleep: onset, maintenance and early rising; daily schedule

WORKSHEET FOR NURSE INPATIENT INTAKE, cont.

- k. Oral issues (dry mouth, secretions, family distress with sound — “death rattle”, ulcers…)
- l. Skin
- m. Speech and ability to vocalize needs
- n. Breathing: note SOB, pain with breathing, anxiety about SOB, issues with cough
- o. Emotional/psychological: (supplement to issues in the adjustment to illness and screen for significant depression and anxiety)
  “Over the past 2 weeks have you:
  - i. felt calm, peaceful, at rest?” How often?
  - ii. felt down, hopeless or depressed or lost interest or pleasure in doing things?”
    ☐ not at all ☐ some of the time ☐ most of the time ☐ nearly all the time
  - iii. felt keyed up, on edge, nervous or anxious?”
    ☐ not at all ☐ some of the time ☐ most of the time ☐ nearly all the time
- p. Spirituality and cultural issues (appendix #3)
- q. Other social, occupational, financial factors

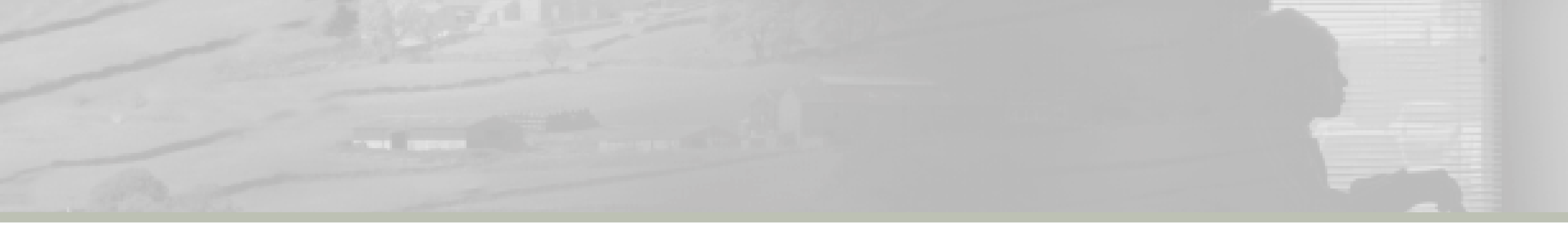
F) List potential problems that carry significant risk of causing crises such as emergency department visits ie. (pain, nausea/vomiting, dyspnea, edema, agitation…)

G) *Patient specific goals:* (Realistic goal setting; Task completion; Defining hope)
- a. LIVING WILL AND DPOA-HC (have they been completed)
- b. List specific wishes of the person “What do you wish you could still do?”
- c. “What are you most proud of? Your greatest accomplishments?”
- d. “What do you still wish to accomplish in your life?”
- e. “If you were to suddenly die — say in a car accident on the way home from the hospital — is there anything you feel would have been left undone? Any dreams you would have wanted to accomplish? Any events or trips you would have liked to take part in? Anything you would have wanted to say to loved ones?”
- f. “After someone they love has died, people often tell me they wished they had made a greater effort to clear the air, to say ‘I love you’ ‘Thank you’ or ‘ask for or give forgiveness.’ Do you think anyone in your life might feel this way?”

H) Education and discussion re resources as appropriate:
- a. Medicare Hospice
- b. Hospice of Littleton Area Volunteers
- c. Other resources or consultations that you would recommend
  - i. Home Health
  - ii. Pastoral care and local clergy
  - iii. Financial resources and social work

Written summary (in the report) should include:
- ◆ Brief initial patient identifiers (ie “65 yo female with Stage IV metastatic breast cancer undergoing 2nd line chemotherapy…)”
- ◆ Most important symptoms for the patient (“… suffering from marked back pain and constipation…”)
- ◆ Key patient goals as listed and why they are important (“… who really wants to be able to garden this summer as it helps her relax and watch.”
- ◆ How medical goals and medical care might be aligned with patient goals
  - • what medical treatments if any might be interfering with patient goals
- ◆ Key recommended consultations and why
- ◆ Other patient specific issues not covered elsewhere in the report

Source: Littleton Regional Hospital, Littleton, NH 03561



SPIRITUAL ASSESSMENT

1. **Is religion or spirituality important to you?**

   ☐ Yes ☐ No

   If no, skip the rest of this assessment.

2. **Are you a member of a church or faith community?**

   ☐ Yes ☐ No

   If yes,
   Name of church or faith community ____

   Do we have your permission to call them and tell them you are here?

   ☐ Yes ☐ No

3. **Would you like a visit from the hospital Pastoral Care Coordinator/Chaplin?**

   ☐ Yes ☐ No

4. **Would you like a visit from an area denominational minister?**

   ☐ Yes ☐ No

   If yes, which denomination? ____

Please ask the Health Unit Coordinator to call minister or Chaplin to schedule a visit.

Intake RN______________________________

Patient Label

Date__________________________________

Source: Littleton Regional Hospital, Littleton, NH 03561

Appendix G: List of Attachments

PALLIATIVE CARE EVALUATION

Reason for Referral ____ *Patient ID Sticker*

Patient Specified Goals

1. ____
2. ____
3. ____

Core Data (pre-hospitalization):

Palliative Performance Scale (PPSv2):

Weight loss in last 6 months:______________________________

Home Bound ☐ Yes ☐ No

Patient is dependent on others for what ADL's:

☐ feeding ☐ transfers/ to bathroom ☐ bathing ☐ continence urine/stool ☐ dressing

DPOA-HC: Living Will: ☐ Yes ☐ No

Services presently provided:

☐ Home Health ☐ Medicare Hospice ☐ HLA Volunteers ☐ Meals on Wheels ☐ HCPCC

☐ Other:____

Physical Symptoms of concern:

1. ____
2. ____
3. ____

Patient Adjustment to Illness and Prognosis/ Transitional stage: ______________________________

____

Other Psychological/ Emotional Symptoms of concern:______________________________

____

Spiritual Needs/Concerns:______________________________

____

Present Major Supports (family, home and other):______________________________

____

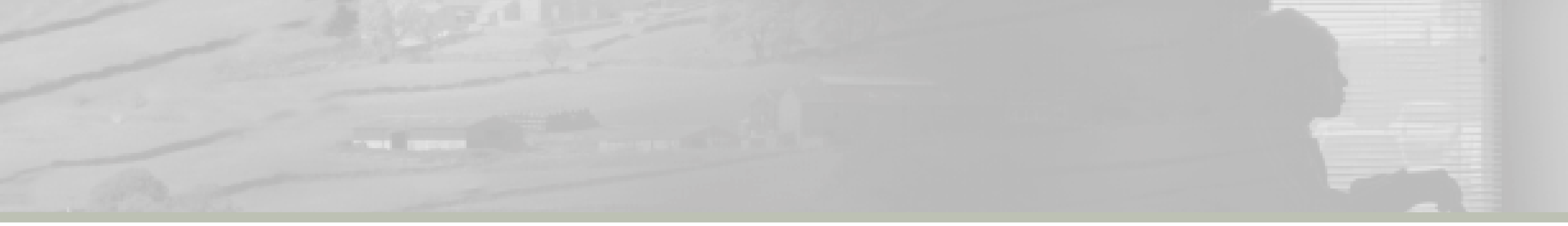
Caregiver Adjustment to Illness and Prognosis/ Assessment of Grief:______________________________

____

Crisis Prevention Plans Recommended for:

1. ____
2. ____
3. ____

Summary:



CONSULTATIONS

✓	**CONSULT** (in addition to what is already being provided)	**PURPOSE**	**Contact Made?** (✓ when done)
	Inpatient		
	Palliative Physician (MD)		
	Anesthesia/Pain ARNP/MD		
	Other Nursing (RN)		
	Hospital Pastoral Care		
	Other Local Clergy:		
	Social Work/Counseling		
	Discharge Planning		
	Financial Counseling		
	Nutrition		
	Pharmacy		
	Medicare Hospice assessment		
	HLA Volunteers		
	Physical Therapy		
	Occupational Therapy		
	Respiratory Therapy		
	Complementary Therapy:		
	☐ Massage		
	☐ Reiki		
	☐ Pet therapy		
	☐ Other:		
	Cardiac Rehab		
	Diabetes Education		
	Outpatient		
	Home Health		
	Medicare Hospice		
	Physical Therapy		
	Occupational Therapy		
	Social Work		
	HLA Volunteers		
	Complementary Therapy		
	☐ Massage		
	☐ Reiki		
	☐ Chiropractic		
	☐ Other:		
	Other		
	☐ Meals on Wheels		
	☐ Crotched Mountain		
	☐ DEAS		
	☐ Other:		

☐ Verbal contact made with referring physician

☐ IDT meeting attended and case reviewed ____________________

Date and time

Patient ID Sticker

____

Intake RN signature, printed name, and date/time

PROPOSED ARRANGEMENT INVOLVING PROVISION OF PALLIATIVE CARE SERVICES

Legal Opinion provided by Arent Fox, courtesy of Connie A. Raffa and Mark B. Langdon

December 22, 2003

Re: Proposed Arrangement Involving Provision of Palliative Care Services

Dear:

This letter is in response to your request for our analysis of potential structures that a hospice might employ in setting up an entity — such as a clinic or professional medical corporation — that would provide palliative care services to patients. We understand that this would be part of an effort to advance the concept of palliative care and potentially reach a broader population not yet appropriate for hospice care.

An approach that has been used with increasing frequency involves a palliative care organization, such as a hospice, assisting physicians in establishing a medical group that contracts with the organization for management and administrative services. The management agreement could be a comprehensive and long-term agreement that provides compensation to the palliative care organization for supplying staff, equipment and space, and general administrative services. Such administrative services could include budgeting and bookkeeping services, arranging for legal and accounting services, purchasing inventory and supplies, assisting in the recruitment of practitioners, maintaining files and records, and assisting in strategic planning. This type of structure is known as a "captive" professional corporation because the non-physician palliative care organization exerts some control over the physician practice through a management services agreement.

Another potentially feasible approach would be for the hospice — consistent with state law and the requirements of the local Medicare contractor — to enroll in the Medicare program as a Part B supplier, or clinic, and bill for non-hospice palliative care services.

Although both of these options are viable ones that can be beneficial to patients, we thought it would be helpful to outline for you some of the legal considerations you will need to be mindful of when developing and implementing your business plan. Please keep in mind when reviewing this discussion that, although the laws set forth below are extremely technical and somewhat intimidating, it is possible to structure palliative care programs within the confines on these laws.

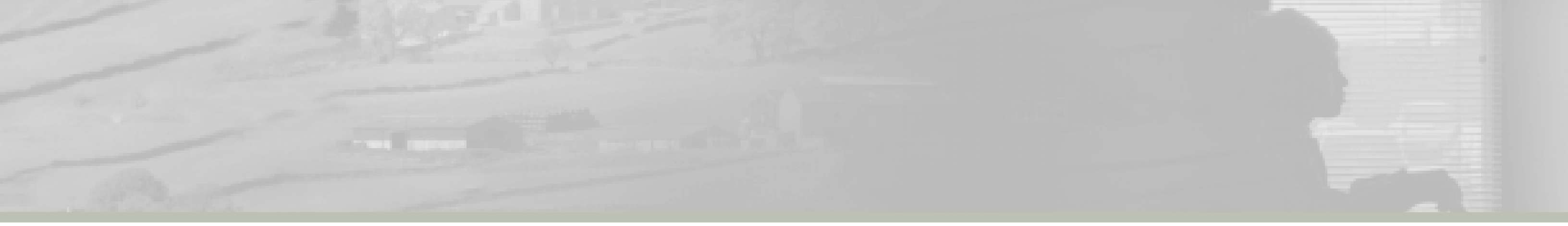
I. Applicable Legal Authorities

A. Federal Anti-Kickback Statute

One of the most significant laws you need to be familiar with when thinking about developing a palliative care program is the Federal Anti-Kickback Statute (the "Anti-Kickback Statute"). This law is a broad prohibition of the offer, solicitation, payment or receipt of anything of value which is intended to induce the referral of a patient for an item or service that is reimbursed by most Federal programs, including Medicare and Medicaid 42 U.S.C. § 1320a-7b(b). The law has been interpreted broadly by several courts to apply to situations where only *one* purpose of a payment is to induce referrals, even if there may be other legitimate purposes for which the payment is made. As a result, virtually any financial relationship between a health care provider and a referral source has potential anti-kickback implications.

Because this law is so broad, several exceptions have been added to it by Congress and by regulations adopted by the Office of Inspector General ("OIG") of the Department of Health and Human Services ("HHS"). Full compliance with one of these exceptions — which are referred to as "safe harbors" — is an absolute defense to an anti-kickback law prosecution by the OIG. Therefore, it is advisable to structure a transaction within a safe harbor whenever possible. To qualify for safe harbor protection, however, *all* of the requirements specified in the applicable statute or regulation must be met.

Most relevant for purposes of an arrangement between a hospice and a palliative care organization would probably be the "personal services and management contracts" safe harbor. The requirements of this safe harbor are as follows:



1. The agreement must be in writing and signed by the parties;
2. The agreement must cover all of the services to be provided for the term of the agreement and specifies the services to be provided;
3. If the agreement is intended to provide for services on a part-time basis, rather than on a full-time basis for the term of the agreement, the agreement must specify exactly the schedule of such intervals, their precise length, and the exact charge for such intervals;
4. The term of the agreement must be for not less than one year;
5. The aggregate compensation paid over the term of the agreement must be set in advance, be consistent with fair market value in arms-length transactions, and not be determined in a manner that takes into account the volume or value of any referrals or business otherwise generated between the parties for which payment may be made in whole or in part under Medicare or a state health care program;
6. The aggregate services contracted for must not exceed those which are reasonably necessary to accomplish the commercially reasonable business purpose of the services; and
7. The services performed under the agreement must not involve the counseling or promotion of a business arrangement or other activity that violates any State or Federal law. 42 C.F.R. § 1001.952(d).

To summarize, any management or administrative services agreement between a hospice and a palliative care clinic would have to meet all of these safe harbor requirements in order for that arrangement to be immune from prosecution under the Anti-Kickback Statute. However, it is important to bear in mind that, even if all of the requirements of the safe harbor cannot be met, the arrangement would not automatically be considered illegal. In fact, some of the requirements — such as the one that the total compensation be set in advance — can be extremely difficult to satisfy. Rather, the determination as to the legality of the arrangement would depend on the intent of the parties. To that end, so long as the compensation reflects fair market value for legitimate and necessary services, such services are actually provided, and the payments do not vary based upon the volume or value of referrals generated between the parties, we believe that the risk of a violation would be low.

It is also important to note that the requirements of the personal services safe harbor would similarly apply to any medical director relationships involving the hospice, the palliative care clinic, and physicians. Further, any equipment and space rental arrangements between the hospice and the palliative care clinic should, to the extent possible, be structured to comply with the requirements of the "equipment rental" and "space rental" safe harbors. 42 C.F.R. § 1001.952(b), (c). The requirements for these safe harbors are very similar to the requirements listed above, but as applied to the lease of equipment and space. The most notable requirement of those safe harbors is that the fees must represent fair market value, and the *total* fee must be set in advance, which means that a fee fluctuating in any manner based upon hours or another basis would not comply with this standard. Again, however, the failure to fully qualify for a safe harbor does not necessarily mean that an arrangement is illegal.

B. The Stark Law

In addition to the Anti-Kickback Law, you also need to consider the implications of any arrangement involving the provision of palliative care services under the Stark Law. The Stark Law prohibits a physician who has a financial interest with an entity (or a physician whose immediate family member has such an interest) from referring a patient to the entity for the furnishing of certain "designated health services" reimbursable by Medicare or Medicaid, unless an exception applies. The designated health services covered by the law include the following: clinical laboratory services; physical therapy services (including speech-language pathology); occupational therapy services; radiology and certain other imaging services; radiation therapy; durable medical equipment; parenteral and enteral nutrients, equipment, and supplies; prosthetics, orthotics, and prosthetic devices and supplies; home health services; outpatient prescription drugs; and hospital services. Penalties for violating the Stark Law include forfeiture of any reimbursement for services rendered based on an unlawful referral, civil fines, and exclusion from the Medicare and Medicaid programs. 42 U.S.C. § 1395nn.

Notably, Medicare-covered hospice services (including the specific designated health services listed above) that are reimbursed *under the hospice composite rate* are specifically excluded from the reach of the Stark Law. However, the Stark Law still might be relevant to the extent that physicians associated with the hospice or the palliative care clinic refer any of the aforementioned services to the hospice or the clinic, and such services are reimbursable outside of the composite rate. In such an instance, the financial relationship between the physician and the hospice or the clinic would have to meet an exception to the Stark Law. And, unlike the Anti-Kickback Law, an arrangement that does not meet an exception to the Stark Law automatically violates the law. Notably, there is an exception for certain referrals that occur within a physician's office, so it is possible that a physician's referrals to the palliative care clinic would be protected.

C. State Anti-Kickback and Self-Referral Laws

In addition to the Federal healthcare fraud and abuse laws discussed above, many states have their own kickback and self-referral laws that apply regardless of whether the patient is a Medicare or Medicaid beneficiary. Sometimes these laws are much broader in scope than the Federal laws; sometimes they are narrower. It is probably safe to assume that compliance with the Federal laws discussed above will reduce your risks under most state laws. However, before proceeding with any business plan, you should engage in a thorough review of the laws in the state(s) where you anticipate doing business.

D. Corporate Practice of Medicine Doctrine

Another significant issue to consider when assessing the development of a palliative care program is whether the relevant state has a "corporate practice of medicine" doctrine that might prohibit, or limit the ability of, a hospice setting up a palliative care clinic. In short, several states have laws which prevent a business corporation or lay person from controlling the medical decisions of a physician and his or her professional staff. With the rise of the physician practice management company over the last decade, many physician practices have ceded aspects of their control of the day-to-day business affairs to business corporations. Such a prohibition would be implicated to the extent that the hospice exercises any control over the medical judgment or professional decision-making of a licensed practitioner.

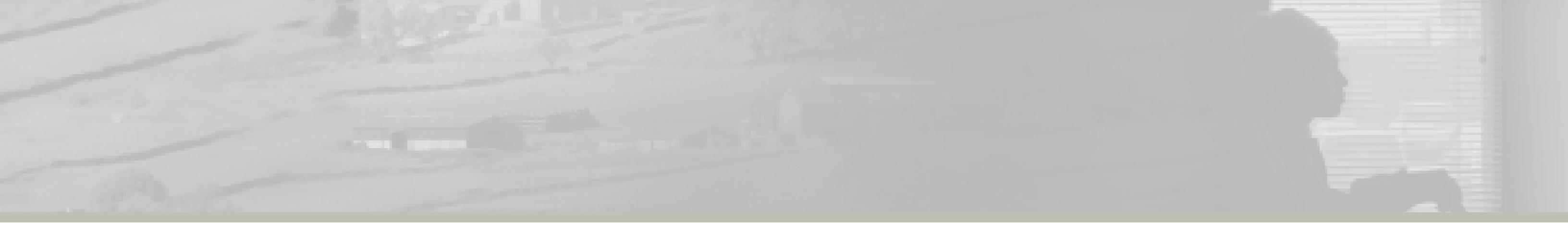
Accordingly, in those states with a relevant corporate practice of medicine law, care must be taken to make certain that the hospice does not exert any control over the professional decisions that are made and executed through the professional corporation. That is, medical decisions made for patients seeking services through the palliative care clinic should be made strictly by licensed professionals practicing through that entity. To the extent that such professional medical decisions and judgments are actually controlled or influenced in any way by the hospice, a risk exists that a state regulatory body could challenge the arrangement as involving the unauthorized practice of medicine by the hospice.

In assessing whether the development of a palliative care clinic is viable from a corporate practice of medicine perspective, the first step would be to determine whether the relevant state has a corporate practice of medicine doctrine. If it does not, then you likely will have more flexibility in how you set up the palliative care entity, who the owners are, etc. If the state does have a corporate practice of medicine doctrine, the next question is whether that state's law would apply to a hospice setting up a palliative care clinic and, if so, how. In addition, you would need to assess whether that state actively enforces its corporate practice of medicine law. That is, although some states have corporate practice of medicine laws on their books, not all of them actively enforce those laws. Considering this issue usually entails contacting the appropriate regulatory officials from the relevant states.

To assist you in determining whether a particular state has a corporate practice of law, we attach to this letter a summary survey chart that was prepared for another client. Please note that this chart should only serve as a guideline — you would need to carefully review the laws of a particular state before deciding whether to proceed. Of course, we would be happy to research one or more of these state's laws if you would like.

E. State Fee-Splitting Prohibitions

Some states also have laws which prohibit physicians from splitting their professional fees with non-physicians. In those states, care would need to be taken when structuring any management fee to be paid by the palliative care clinic to the hospice. In addition to being commensurate with the fair market value of the services provided, in certain states, the fee could not be based upon a percentage of revenues or collections of the clinic. In all instances, appropriate documentation of the services provided, and the fees paid for these services, should be maintained.



II. Additional Considerations

We now turn to a few additional issues that might be relevant to a hospice setting up a palliative care clinic.

A. Discharge of Patients

A potential issue is whether there are any restrictions or limitations on the ability of the hospice to refer patients to the clinic upon discharge from the hospice. As set forth above, the financial arrangements between the hospice and the clinic, the hospice and the its medical director and employee, and the clinic and its physicians (and other professionals in a position to refer) must be consistent with fair market value, and to the extent they are not, there is a risk that a regulatory agency, or a court, could find that the arrangements involve prohibited remuneration intended to induce referrals.

As to whether there are any additional specific legal authorities relevant to the referral of patients from a hospice provider, we note that Section 4321 of the Balanced Budget Act of 1997, which sets forth certain restrictions applicable to the discharge planning process, applies to referrals from a *hospital* for home health services and hospice (and possibly all other post-hospital services). Accordingly, to the extent that a hospital patient can be appropriately discharged to a hospice, the hospital should furnish a list of all relevant providers in the geographical area to that patient.

B. Physician's Role As Hospice Medical Director And Sole Owner Of Professional Corporation

Another potential issue concerns the dual role of the hospice medical director, who might also serve as an owner of the palliative care clinic. Because this physician might be in a position to influence referrals from the hospice to the clinic, as well as from the clinic to the hospice, aside from making certain that his compensation reflects fair market value, it is also very important to ensure that appropriate documentation of the time he spends in both his capacity as a medical director and an owner is maintained. Specifically, the physician's time reports should record the amount of hours he spends each week as the hospice medical director as well as the clinic owner, and, at least with respect to his medical director functions, those records should (consistent with 42 C.F.R. § 418.64) set forth the specific medical director duties he provides. To the extent that the physician is compensated by the hospice for providing medical director services when, in fact, he is functioning in his capacity as the owner of the clinic, this could be viewed as a kickback by the hospice to the clinic. Similarly, if the physician is not treated as a bona fide owner and employee of his clinic (i.e., if he receives a nominal salary), a risk exists that this would be viewed as an arrangement involving a kickback from the clinic to the hospice, as the hospice would arguably be assuming a financial obligation of the clinic (i.e., the hospice would essentially be paying the physician's salary in his capacity as an employee of the clinic). In addition, there is a risk that the corporate practice of medicine doctrine would be implicated (in those states that have a relevant corporate practice of law) to the extent that the physician receives little to no salary from the professional corporation, as this would make it appear that the hospice, rather than the clinic, maintains overall responsibility for providing professional medical services.

III. A Hospice Enrolling As a Part B Supplier

As we have previously discussed, following a meeting earlier this year between the National Association of Home Care and Hospice ("NAHCH") and officials at the Centers for Medicare and Medicaid Services ("CMS"), NAHCH released a newsletter entitled "Hospice How To: Becoming a Part B Supplier." Although it is not impermissible for a hospice to become a Medicare Part B Supplier in order to bill for non-hospice palliative care for Medicare beneficiaries, care must be taken to review the viability of this approach under the state and Federal laws outlined above. In addition, the hospice should communicate with its Part B contractor to determine what additional requirements might apply.

* * * *

We hope that our discussion set forth above has been helpful to you in considering the various health care regulatory issues involved in a hospice setting up a palliative care clinic. To the extent that you would like us to elaborate on more specific options that might be available in particular states, please let us know. In the meantime, feel free to contact us should you have any questions.

Very truly yours,

Connie A. Raffa

Mark B. Langdon

Enclosure

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THE HUMAN CARING INITIATIVE

Development Plan

A Vision for Clinical and Cultural Change

The Human Caring Initiative is comprised of three components:

The Palliative Care Service
The Center for Human Caring
The Institute for Human Caring

MISSION

Transforming the way people are cared for through the end of life.

Responding to the needs of people in northern New England and recognizing an opportunity to contribute to local and national efforts to improve comprehensive care through the end of life, Dartmouth-Hitchcock Medical Center (DHMC) proposes a strategic Human Caring Initiative.

Through excellence in clinical care, teaching, research and community-based quality improvement, DHMC seeks to lead a transformation in clinical care, community support and cultural maturation surrounding the way people are cared for and die.

Overview

Palliative Care at Dartmouth-Hitchcock Medical Center

Responding to a national crisis that surrounds the way too many Americans die, Dartmouth-Hitchcock Medical Center (DHMC) and Dartmouth Medical School (DMS) recognize an historic opportunity to extend clinical and cultural leadership in human caring through the end of life.

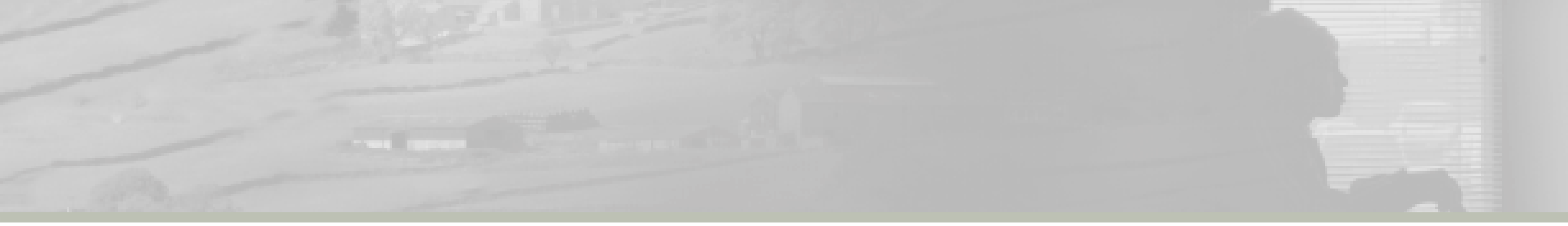
Dartmouth-Hitchcock Medical Center has a well-earned reputation for clinical excellence that combines technical expertise with personalized caring, communication and shared decision-making that keeps the patients and the families we serve at the center of attention.

In health care, history alone does not ensure success. As an authentic leader in health care, DHMC does not rest on laurels. Well-functioning systems, a commitment to core values, continual assessment of performance and continual quality improvement, attention to the culture of caring, the working environment and the well-being of clinical and support staff all contribute to delivering care that sets national standards. The Palliative Care Service at DHMC has developed this Human Caring Initiative consistent with DHMC's commitment to excellence in all realms of caring.

"The Best Care Possible through the End of Life"

The vision of the Human Caring Initiative is delivery of care in a way that combines the very best of evidence-based medicine — including state-of-the-art comprehensive symptom management — with unabashedly tender loving care and community-based support for people facing life's end. Simply stated, we believe that by taking "the best care possible" of each patient and family we serve, we can lead by example — alleviating suffering and preserving opportunity through the end of life and during grief.

Dartmouth-Hitchcock Medical Center and Dartmouth Medical School encompass centers of excellence in care and research. These include the Norris Cotton Cancer Center, a Level I regional trauma center, CHaD (the Children's Hospital at DHMC) to



name just a few. In 2003 DHMC earned Magnet status, a prestigious national recognition of its center-wide excellence in nursing.

As essential as medical and nursing skills are to caring well for people through the end of life, even the very best health care by itself is not sufficient. The fundamental nature of dying is not medical, it is *personal.*

Peoples' lives are lived in families and within communities that comprise our cities, towns, neighborhoods, places of work, and places of worship. The Human Caring Initiative recognizes that our caring attention must extend to social, emotional and spiritual dimensions of their experience. The relatives and close friends who comprise a person's "family" deserve practical support in their caregiving, and emotional and spiritual support during times of grief. "The best care possible" must also seek to strengthen bonds that connect people to the network of relatives, friends and communities in which they have lived.

Tender Loving Care

The eminent surgeon of the early 20th century, Francis Peabody, observed, "One of the essential qualities of the clinician is interest in humanity, for the secret of care of the patient is in *caring for* the patient."

One of his students, Dr. J. Englebert Dunphy, who went on to become Professor and Chair of Surgery at University of California at San Francisco reflected, "Francis Peabody's dictum... permeated our student days. We learned that the practice of medicine is cold and abrasive unless tempered by love."

The phrase, "tender loving care" is the sine qua non of excellence in our culture. There is nothing within the ethics or principles of medicine that disallows human love. Touching suffering or dying patients with the intention of providing comfort and even eliciting pleasure is entirely appropriate and wholesome. Loving care opens up a wide realm of therapeutic modalities. Gently massaging an ill patient's hands or feet, or oiling the person's skin can be soothing interventions. Soft songs or lullabies, prayers or silent visiting can all ease distress and improve quality of life for people in distress.

Leadership by Example

Dartmouth-Hitchcock Medical Center's leadership within health care in northern New England and strong ties to the communities it serves create a unique opportunity to lead by example. We are developing systems of caring that integrate state-of-the-art medical treatment with formal and informal community-based services that raise the bar for health care and exemplifies clinical-community collaborations.

Illness, caregiving, dying and grief are all local. The real change that is needed is not merely medical — it is social and cultural. Comprehensive, competent health care is necessary, but not sufficient. This superior level of care requires the active involvement of communities. We can seed our collective cultural imagination with examples of excellence in care and personal experience that can "expand the realm of the possible" through the end of life for our nation.

One Person at a Time

Excellence in care is delivered one person and one family at a time. In active collaboration with our colleagues in the specialties and subspecialties of medicine and surgery, the Palliative Care Service at DHMC strives to deliver the best care possible to each patient and family we serve. While keeping our clinical focus local, we recognize the opportunity — and feel a responsibility — to study, continuously improve and report our experience broadly. The vision and goal is to deliver "the best care possible through the end of life" for patients who are seriously ill, aging or injured and provide their families with the support they need in a manner that raises the bar — locally and nationally.

Source: For more information, contact The Palliative Care Service, Dartmouth-Hitchcock Medical Center, One Medical Center Drive, Lebanon, NH 035756, 603-650-5402.

CENTER TO ADVANCE PALLIATIVE CARE

National Hospice and Palliative Care Organization

NRHA

Providing Hospice and Palliative Care in Rural and Frontier Areas

Acknowledgements

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List of providers interviewed for the Rural Toolkit:
(Including site visit, short questionnaire and phone interviews)

Region A: Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont

- Central Vermont Home Health & Hospice, Inc., Barre, VT
- VNA and Hospice of VT and NH, White River Junction, VT
- High Peaks Hospice, Saranac Lake, NY
- Littleton, NH, Palliative Care Coalition including:
    1. Phil Lawson, MD, project advocate and practicing physician
    2. North Country Home Health and Hospice Agency
    3. Hospice of the Littleton Area
    4. Littleton Regional Hospital
- Coastal Hospice, Salisbury, MD

Region B: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, West Virginia

- Hospice Care Corporation, Arthurdale, WV
- Covenant Hospice, Pensacola, FL
- Hospice of the Bluegrass, Lexington, KY
- Hospice of Central Kentucky, Elizabethtown, KY
- Dare Home Health and Hospice, Manteo, NC
- Palliative Care Institute of Southeast Louisiana and Hospice of St. Tammany, LA
- Hospice and Palliative Care of Louisville, KY

Acknowledgements

Region C: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin, Iowa, Kansas, Missouri, Nebraska

- Hospice of North Iowa, Mason City, IA
- Lutheran Home Care Agency and Hospice, Frankenmuth, MI
- Hope Hospice, Rib Lake, WI
- Hospice Services, Inc., Phillipsburg, KS
- Prairie Haven Hospice, Scottsbluff, NE
- Hospice of Siouxland, Sioux City, IA

Region D: Arizona, California, Hawaii, Nevada, New Mexico, Oklahoma, Texas

- University of California-Davis, Robert Wood Johnson Foundation grant for rural hospice outreach, Davis, CA
- University of New Mexico, Creating a Palliative Care System, Albuquerque, NM
- Cross Timbers Hospice, Ardmore, OK
- VistaCare, Hobbs, NM

Region E: Alaska, Colorado, Idaho, Montana, Oregon, Utah, Washington, North Dakota, South Dakota, Wyoming

- Sioux Valley Hospital/University of South Dakota Medical Center Adult Palliative Care Consultation Team and Sioux Valley Hospice, Sioux Falls, SD
- Hospice of the Red River Valley, Fargo, ND
- Hospice of the Wood River Valley, Ketchum, ID
- Hospice and Palliative Care of Western Colorado, Grand Junction, CO
- Helping Hands Project, Hospice of Anchorage, Native Alaskan Tribal Health Consortium, AK
- Hospice of Redmond, Sisters and Grant Counties, Redmond, OR
- Big Sky Hospice, Billings, MT
- Sidney Health Center Hospice, Sidney, MT
- St. Benedicts Health Care Center, Dickinson, ND