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# Providing hospice care in rural areas: Challenges and strategies

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## Abstract

*Hospices in rural settings face challenges in the provision of hospice care as a result of their location and the size of their service area population. To ascertain the challenges that hospices face in serving rural communities, researchers conducted in-depth case studies of four different models of hospice care in rural areas. The authors describe strategies used by the case study hospices and recommend policies that could increase access to hospice care for rural Medicare beneficiaries and other rural residents. National initiatives to*

*improve end-of-life care need to consider the special challenges faced by rural hospices.*

*Key words: hospice, rural, end-of-life care, cost of care*

## Introduction

Over 1.7 million elderly Medicare beneficiaries die each year, with rural beneficiaries accounting for almost one-fourth of the deaths.<sup>1</sup> Although use of the Medicare hospice benefit has grown significantly over the last decade, many dying patients continue to suffer from untreated or undertreated pain and other symptoms that could be relieved by better access to palliative care.<sup>2,3</sup> Rural Medicare beneficiaries are significantly less likely than urban beneficiaries to use hospice care, raising questions about whether all beneficiaries have equal access to the Medicare hospice benefit.<sup>1,4-6</sup>

As the largest payment source for hospice care in the United States, the Medicare program has a significant influence on hospice use and the financial status of hospices.<sup>7</sup> Medicare per diem rates are consistently lower for rural hospices than urban hospices because they are adjusted using a hospice

wage index.<sup>8</sup> However, the rates are not adjusted for other differences in costs that may be significantly higher for rural hospices, such as travel to patients' homes. Recent studies, including an actuarial analysis of hospice costs and revenues, suggest that many hospices, especially small rural hospices, are likely to have costs that are not adequately covered by the current Medicare payment system.<sup>9-11</sup>

Home-based hospice care is labor intensive. The task of recruiting and retaining staff is complicated by the need to accommodate fluctuations in patient census and to provide coverage 24 hours a day, seven days a week. For rural hospices, staffing challenges are exacerbated by shortages of nurses, social workers, and other health professionals. Rural hospices with low patient volumes are often unable to fund full-time positions, and those that cover large geographic areas may have difficulty finding staffing willing to travel to remote areas. Hospice workers may be at particular risk for burnout and compassion fatigue in resource-poor rural areas, especially when the boundaries between their work and personal lives are blurred.<sup>12</sup>

In 2002, the hospice median length

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of stay was 21 days, and more than one-third of hospice patients died in seven days or less.<sup>13</sup> Analysis of survival times has demonstrated that the majority of Medicare hospice patients enroll in hospice relatively late in their terminal illness.<sup>14,15</sup> Late referrals and nonuse of hospice services occur for many reasons, including difficulty accurately predicting the length of time a terminally ill patient has left and reluctance on the part of many physicians, patients, and family members to stop aggressive treatment.<sup>4,17,18</sup> Late referrals make it difficult to provide patients with optimal pain and symptom management and help them come to closure with end-of-life (EOL) issues. Very short lengths of stay also have a negative impact on the financial status of hospice organizations, because the first and last few days of hospice care tend to be the most costly.

Because of their low volume, small rural hospices are more vulnerable to financial difficulties arising from trends across the entire hospice industry, such as late referrals and declining lengths of stay. They have fewer patients over which to spread fixed costs and are especially vulnerable to financial problems arising from high-cost outlier cases, since Medicare per diem reimbursement is based on average costs for a hospice caseload.<sup>1</sup> Small hospices also are less likely to benefit from economies of scale in purchasing pharmaceuticals and medical supplies.

To date, limited research has been conducted on the provision of hospice care in rural areas. Based on in-depth case studies of four hospices, this article describes the challenges that hospices face in serving rural communities and strategies used to address them. It discusses factors that influence the appropriateness of a hospice model for a specific rural area and makes policy recommendations to increase access to hospice care for rural Medicare beneficiaries.

## Methods

Researchers identified all Medicare certified hospices serving rural patients in 1999.<sup>1</sup> These hospices formed the basis for selecting case study sites. The researchers sought representation of each of the most common organizational models for hospices in rural areas: hospital-based (35 percent), freestanding (34 percent), and home health agency-based (31 percent). Other factors considered in site selection included the region, size, and age of the hospice. Several state hospice associations were asked to recommend case study candidates, and hospice directors were contacted for additional information.

Four hospices were selected representing different models for providing hospice care in rural areas: 1) Kanabec County Public Health Hospice in Mora, Minnesota, a small and relatively new rural hospice program run by a public health agency in conjunction with a home health program; 2) Lower Columbia Hospice in Astoria, Oregon, a hospital-based rural hospice with a long history as a volunteer program and 10 years as a Medicare-certified hospice; 3) Regional Hospice Services, a freestanding hospice with four rural sites in northern Wisconsin and upper Michigan and nine years of Medicare certification; and 4) Hospice of North Central Florida, a large and long-established freestanding hospice based in urban Gainesville with three rural sites (Table 1).

The case studies involved two-day site visits by a two-person team (except for the Minnesota site, where a four-person team conducted a one-day visit) between September 2001 and March 2002. At each hospice, interviews were conducted with key hospice management and staff including the hospice director, medical director, nursing supervisor, social work director, volunteer coordinator, chaplain, nurses, and social workers.

Team managers and staff at four satellite sites, two in Florida and two in Wisconsin, also were interviewed. Physicians, administrators, and staff at hospitals and nursing homes who work with the hospice were interviewed in each community. Additional interviews were conducted with hospice patients and family members of patients at three sites; board members and home health aides at two sites; and a volunteer at one site.

A total of 61 in-person and three phone interviews were conducted using semi-structured protocols. Interview topics included the hospice history, organizational structure, staffing, services, service area, utilization, relationships with other healthcare providers, and financial and regulatory issues. Written interview summaries were analyzed to prepare the case studies and identify common themes. Each hospice reviewed its case study for accuracy.

## Results

The case studies illustrate the challenges facing hospices that serve rural populations and demonstrate how hospices with different organizational characteristics and at various stages of development operate in diverse rural communities and healthcare systems.

### *Financial challenges*

In each case study hospice, Medicare and insurance reimbursements were not sufficient to cover costs. All four hospices relied on fundraising and donations to help cover operating expenses. Only the large urban-based regional model, Hospice of North Central Florida, had a positive financial margin. Prior to its recent large growth in patient volume, this hospice also experienced revenue shortfalls and received financial support from a sponsoring hospital and health system. Two of the three smaller rural-based hospices, Regional

**Table 1. Characteristics of rural hospice case-study sites**

Hospice and location	Date established	Medicare-certified	Structure and ownership	Service area	Number of patients	Staffing
Kanabec County Public Health Hospice, Mora, MN	1998	1999	rural-based, home health agency-based government owned (county public health department)	one rural county, population 14,996; 28.6 persons/sq. mile	20 patients in 2000	Public health director oversees the hospice program. A home care nursing supervisor, six nurses, a home health aide supervisor, and 17 home health aides care for hospice and home health patients. Part-time medical director, hospice social worker, and chaplain, and 15 volunteers.
Regional Hospice Services, Inc., Ashland, WI; satellite sites in Hayward and Spooner, WI, and Ironwood, MI	1991	1992	rural-based, free-standing agency with four rural sites not-for-profit, sponsored by four community hospitals	13 rural counties and one urban county, population 291,396; 19.5 persons/sq. mile	193 patients in 2000	At year-end 2000, the hospice had a total of 17.5 full-time equivalent staff. Full-time executive director, RN clinical director, and the social service director. Part-time nurses whose work hours vary with patient caseload. Part-time social workers and chaplains, and 58 volunteers.
Hospice of North Central Florida, Gainesville, FL; satellite sites in Chiefland, Lake City, Palatka, and Jacksonville, FL	1978	1985	urban-based, freestanding agency with three rural sites not-for-profit 18 bed inpatient/residential hospice	11 rural and five urban counties, population 807,792; 161.5 persons/sq. mile	2,281 patients in 2001 (1,295 rural and 986 urban)	In 2001, the hospice had a total of 195 full-time equivalent employees organized into care teams for each site and for the residential care center. The hospice averages about 70 volunteers per site.
Lower Columbia Hospice, Astoria, OR	1981	1991	rural-based, administered and staffed, in part, jointly with home health program Not-for-profit, hospital-owned five-bed adult foster home residential hospice	one rural county, population 35,630; 43.1 persons/sq. mile	129 patients in 2001 including 34 patients at adult foster home	Hospice staff are hospital employees. Manager, administrative staff, home health aides shared between hospice and home health programs. Separate hospice nursing staff includes RN patient care coordinator, four half-time staff nurses, and a relief nurse. Part-time medical director, social worker, chaplain, and 18 volunteers. Adult foster home manager and six staff work rotating shifts to provide 24 hour coverage.

Data sources: hospice site visits; US Census 2000; Area Resource File 1999.

Hospice Services and Lower Columbia Hospice, were receiving financial subsidies from sponsoring hospitals, while shortfalls in the Kanabec County hospice budget were covered by county funds.

The hospices all identified the distances traveled to patients' homes as a major challenge to serving rural areas. Hospice workers travel up to 60 miles one way to serve patients, and occasionally travel beyond their official service areas to serve patients who would otherwise not have access to hospice care. In addition to travel costs, the time spent traveling limits time available for direct patient care. The long distances traveled complicate on-call coverage, and staff safety is a concern in isolated areas. Severe winter weather makes travel more difficult in the Midwestern sites, and seasonal flooding poses problems in Oregon.

Medication costs are another financial challenge, especially for the smaller hospices. Kanabec County Hospice and Regional Hospice Services obtain medications for their hospice patients from local pharmacies, which are very costly. At the time of our site visit, the Kanabec County Hospice was caring for a patient with pain medication costs of \$3,000 per month—an amount equivalent to the entire per diem received for care of the patient. The hospital-based hospice, Lower Columbia Hospice, was using the hospital pharmacy for medications at the time of our visit. Although the hospice staff was pleased with the hospital pharmacy services, the hospice began using a national direct delivery pharmacy service for patient medications in May 2002 because of the volume of work experienced by the hospital's pharmacists and the hospital's difficulty recruiting pharmacists. The hospice anticipated that this change would increase its medication costs significantly.

Hospice of North Central Florida

directly contracts with a network of over 70 local pharmacies to provide medications rather than having its own central pharmacy. This ensures the timely delivery of medications over its extensive service area. By negotiating pharmacy contracts jointly with the AvMed Health System, the hospice was able to obtain more favorable contracts.

The smaller case study hospices generally did not provide high-cost treatments, such as expensive palliative radiation or chemotherapy, citing an insufficient volume of patients over which to spread these costs under the per diem payment system. Hospice of North Central Florida's large patient volume allows it to provide more specialized services, including radiation, chemotherapy, and dialysis, when appropriate, to palliate symptoms in hospice patients.

#### *Hospice staffing*

Hospices serving rural areas, especially low-volume hospices and those with large service areas, face challenges recruiting and retaining staff and providing coverage 24 hours a day, seven days a week. The case study hospices employ a variety of strategies to address staffing needs. One strategy is to employ hospice staff from a parent agency, which provides the employees with salaries and benefits comparable to similar positions in the larger organization. The staff members of Kanabec County Hospice are county employees, and Lower Columbia Hospice staff members are hospital employees. A related strategy is sharing staff across programs. The Kanabec County Public Health Agency jointly staffs its hospice program and its much larger home health program; nurses have both hospice and home health patients in their caseloads. The chaplain at Lower Columbia Hospice ministers to both hospice and hospital patients.

Joint staffing can help an agency deal with fluctuations in hospice census and help to even out caseloads geographically, thereby reducing staff travel. It also can reduce staff burnout by providing variety in patient caseloads and spreading responsibility for on-call coverage over a larger number of workers.

Some of the staff members at the three smaller hospices perform multiple roles. For example, volunteer coordinator responsibilities are part of a social work, nursing, or home health aide position. These hospices also employ part-time medical directors, nurses, and social workers. The part-time staff are either semi-retired, seeking to balance work time with family needs, or have other practice interests. Hospice of North Central Florida's larger organizational structure allows it to provide competitive salaries and benefits, such as health insurance and retirement benefits, which facilitate recruitment. It also achieves efficiencies related to centralized administration and shared on-call coverage for nurses and social workers.

#### *Physician referrals and coordination of care*

While not unique to rural areas, physicians' attitudes toward hospice are a key factor influencing the number and timing of hospice referrals. In the case study communities, physicians' attitudes towards hospice ranged from strongly supportive to negative. The majority of physicians are willing to make hospice referrals, particularly if requested by the patient and family. However, hospices face additional challenges in rural areas where there are physician shortages, high physician turnover, or where a significant portion of patients obtain medical care outside the local community. It is more difficult for a hospice to coordinate patient care when community physicians are overworked or

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there is considerable turnover, which forces the hospice medical director and staff to spend more time developing physician relationships.

The task of coordinating care for hospice patients across healthcare settings should be somewhat easier in smaller rural communities with fewer healthcare organizations. Kanabec County, for example, has only one physician group practice, one hospital, and one nursing home, thus simplifying coordination. However, a significant portion of county residents receive some healthcare from providers outside the community, making coordination of care for these patients more difficult.

Depending on the organizational structure of the hospice and the local healthcare market, rural hospices may compete with nursing homes, home health agencies, and hospitals in their service area for patients and staff. In the rural communities visited in the study, the hospices generally had positive relationships with local hospitals. Lower Columbia Hospice's hospital-based status has provided financial stability and helped with staffing. Regional Hospice Services has strong organizational and financial ties to the four hospitals in its local communities through the hospitals' active role on the hospice board and provision of ongoing financial and in-kind support. A number of the rural hospitals have a special hospice room for inpatient care and have adopted policies to facilitate inpatient admission of hospice patients. Designation of a hospice nurse as a liaison for each hospital facilitates cooperative relationships with hospital staff and promotes continuity of care for hospice patients in those facilities.

The hospices' relationships with nursing homes and home health agencies are more complex. Several nursing home administrators described their local hospice as a resource for staff in-service training on pain management and palliative care. However,

some nursing homes appear reluctant to refer patients for hospice care because of reimbursement issues as well as staff perceptions that hospice does not add much to their own care of dying patients.

## Discussion

The appropriate hospice model for a specific rural area depends on the size, density, and demographic characteristics of the service area population; the configuration of the local healthcare system; relationships between local providers; and how other healthcare services are being provided. To be financially viable, rural hospices must obtain a sufficient volume of patients. Successful strategies to achieve economies of scale may include sharing of fixed costs, joint management and staffing, and purchasing of medical supplies and pharmaceuticals in cooperation with a parent agency or through other options such as group purchasing.

A regional model that serves a large rural service area with satellite sites can achieve a sufficient volume of hospice patients, particularly if the hospice is based in an urban area or in a rural community with a relatively large population base. To be successful, a regional model with multiple sites needs to achieve a balance between centralizing administrative functions and maintaining a strong sense of a community hospice at the local level. This involves having local staff members who develop relationships with community physicians and other healthcare providers as well as keeping donations local. A successful regional model also requires significant effort to build relationships, coordinate implementation of policies and procedures, and maintain ongoing communication between hospice administrative and direct-care staff across multiple sites.

Hospital-based or home health

agency-based hospice models can facilitate continuity of care for patients who move from the hospital or home healthcare to hospice, and for hospice patients who are hospitalized. They also can reduce or eliminate competition for patients and staff between the hospice program and the hospital or home health agency. A key issue for these models is maintaining a focus on the hospice mission and philosophy, especially if hospice patients account for a small percentage of the patients in the larger organization.

To determine what type of model should be used to provide hospice services in a rural community, caregivers should evaluate current healthcare utilization and referral patterns, such as where residents are usually hospitalized or referred for specialty care. Community trust in the organization selected to provide the service and agreement among healthcare providers about the decision are key to the success of the hospice. In Kanabec County, for example, the hospital supported the decision to have the public health agency provide hospice services. Hospital staff felt that the service should be provided locally so that patients would not have to change physicians to use hospice services, and thought that it made sense for the public health agency to provide the hospice services since it was already providing home health services.

The ability to achieve economies of scale by maximizing the volume of hospice patients to be served through a regional program, or through joint staffing and purchasing through a parent agency, is very important. Thus, a rural community that is located within reasonable proximity to a well-established hospice program in a larger rural or urban community may consider establishing its hospice program as a satellite of the larger program. Alternatively, a rural community with a well-established hospital-based or freestanding home health program

may consider establishing a hospice program in cooperation with the home health program.

The hospices profiled in this study are implementing multiple strategies to address the financial and staffing challenges faced by hospices serving rural patients, but national initiatives are needed to improve overall access to hospice care for terminally ill rural Medicare beneficiaries. Reflecting adjustments to the hospice wage index, Medicare payments to rural hospices overall will increase 2.9 percent for fiscal year 2005 compared with 0.7 percent for urban hospices.<sup>8</sup> Nonetheless, the Medicare program still needs to evaluate hospice payment rates to ensure that they are consistent with the costs of providing appropriate care in rural areas.<sup>1,9,18</sup> Critical issues to be addressed include rural hospice travel costs and the need for a patient-level outlier payment policy for high-cost cases in low-volume hospices.

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