

**Models for Providing Hospice Care in Rural Areas:  
Successes and Challenges**

*Working Paper Series*

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## **EXECUTIVE SUMMARY**

Rural Medicare beneficiaries are significantly less likely than urban beneficiaries to use hospice care, but limited research has been conducted on the provision of hospice care in rural areas. The purpose of this study is to describe how four different hospice models provide hospice care in rural areas, using a qualitative case study approach.

Kanabec County Public Health Hospice in Mora, Minnesota was established in 1998 and served 20 patients in 2000. It is based in a home health agency that is part of the county public health department. The Lower Columbia Hospice in Astoria, Oregon, is a hospital-based program that was established in 1981 and Medicare certified in 1991. It served 129 patients in 2001. Regional Hospice Services, based in Ashland, Wisconsin, is a freestanding agency that serves a large, sparsely populated area of northern Wisconsin and the Upper Peninsula of Michigan. With four rural sites, it served 193 patients in 2000. Hospice of North Central Florida, based in Gainesville, Florida, is a very large, freestanding regional model hospice that serves a 16 county area. It started in 1978, was Medicare certified in 1985, and served a total 2,281 patients, including 1,295 rural patients, in 2001.

Many of the lessons learned from the case studies have implications for hospices in other rural settings and for public policy regarding the provision of hospice care. The lessons learned include:

- Rural hospices face additional financial challenges beyond those arising from trends affecting the entire hospice industry, such as shorter lengths of stay and increasing medication expenses. Travel costs are an important financial issue for many rural hospices.
- 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, 7 days a week.
- Concern about late referrals to hospice care and the need to improve pain management for dying patients are common themes across different types of rural hospice models.
- The smaller size and limited number of health care organizations in rural communities make the task of coordinating care for hospice patients across health care settings somewhat easier in rural areas than in many urban areas. However, coordination between hospices and hospitals, nursing homes, and home health agencies in rural communities on end-of-life issues is still complicated by organizational “turf” issues and Medicare and Medicaid reimbursement policies.

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- Residential options are needed in rural areas for hospice patients without a caregiver at home, or who are too ill to be cared for by an elderly spouse. However, these programs require considerable financial support from a community.
- The appropriate hospice model for a specific rural area depends on a variety of factors, including the size, density, and demographic characteristics of the population in the service area, the configuration of the local health care system, relationships between local providers, and how other health care services are being provided in the area.

The results of these case studies indicate that hospices in rural settings, while sharing common goals with those serving urban areas, face special challenges that have limited access to hospice services for rural residents. The challenges faced by hospices in rural settings should be considered in designing and implementing state and national initiatives to improve end-of-life care through changes in health professional education and health care financing, especially the Medicare program.

## **INTRODUCTION**

Regardless of their location, hospice programs share certain common goals. They strive to help patients have a good quality of life while they live, and to die with dignity and as comfortable and pain-free as possible. They also work to support families in caring for their family member at home if possible, and in dealing with their grief. At the same time, hospices in rural settings also face special opportunities and challenges in the provision of hospice care as a result of their location, and the size of the population in their service area.

Medicare beneficiaries account for a large proportion of hospice patients, and Medicare is by far the largest payment source for hospice care in the United States, accounting for over three-fourths of hospice revenues (Gage et. al., 2000). Therefore, Medicare payment policies have a substantial influence on the financial viability of hospices. Previous research using Medicare administrative data has found that rural Medicare beneficiaries are significantly less likely than urban beneficiaries to use hospice care (GAO, 2000; MedPAC, 2000, 2002; Virnig et. al., 2000, 2002). To date, however, there has been limited research on the provision of hospice care in rural areas or the reasons for rural-urban differences in hospice use rates.

The purpose of the current study is to provide an in-depth perspective on how different hospice models provide hospice care in rural areas, using a qualitative case study approach. This study documents the successes that different types of hospices have achieved in serving rural communities. It also describes the challenges faced by the hospices, in an effort to explain why rural Medicare beneficiaries have significantly lower hospice use rates than urban beneficiaries.

## **METHODS**

Data from the Centers for Medicare and Medicaid Services (CMS) Medicare Provider of Service File and 100% Hospice File were used to identify all Medicare certified hospices serving rural patients as of 1999, and to determine the distribution of hospices by location, organizational structure, ownership status, and the number of rural Medicare beneficiaries served in 1999 (Table 1). Hospice use rates by state were also examined. Based on the distribution of hospices according to the above criteria, a list of potential sites for hospice case studies was developed, and hospice associations in several states were contacted for recommendations about hospices in their states that would be good candidates for case studies. Several hospice directors were then contacted by phone for additional information about their hospices, and to ask about their willingness to participate in a site visit.

The case study hospices were selected to represent diverse hospice models that varied by geographic region (Midwest, West, South), the date the hospice was established (1979-1998), organizational structure (freestanding, hospital-based, home health agency-based), ownership status (not-for-profit, government), the number of patients served (very small to very large), location and service area (rural-based serving one rural county, rural-based serving multiple rural

counties using satellite sites, urban-based serving multiple rural and urban counties using satellite

**Table 1**

**Medicare Certified Hospices by Location, Organizational Type, Ownership  
and Census Region 1999  
(n=2,254)**

	Urban <sup>1</sup>	Rural Adjacent <sup>2</sup>	Rural Non- Adjacent <sup>3</sup>	Total
<b>Organizational Type</b>				
Hospital-based	255 (18.4%)	115 (30.5%)	190 (38.9%)	560 (24.8%)
Home health agency-based	503 (36.2%)	129 (34.2%)	136 (27.9%)	768 (34.1%)
Freestanding	613 (44.1%)	131 (34.7%)	160 (32.8%)	904 (40.1%)
Skilled nursing facility	18 (1.3%)	2 (0.5%)	2 (0.4%)	22 (1.0%)
<b>Ownership</b>				
Non-profit	864 (62.2%)	251 (66.6%)	288 (59.0%)	1,403 (62.2%)
Proprietary	458 (33.0%)	67 (17.8%)	91 (18.6%)	616 (27.3%)
Government	43 (3.1%)	36 (9.5%)	75 (15.4%)	154 (6.8%)
Other	24 (1.7%)	23 (6.1%)	34 (7.0%)	81 (3.6%)
<b>Census Region</b>				
Midwest	330 (23.8%)	132 (35.0%)	192 (39.3%)	654 (29.0%)
Northeast	265 (19.1%)	49 (13.0%)	21 (4.3%)	335 (14.9%)
South	498 (35.9%)	146 (38.7%)	170 (34.8%)	814 (36.1%)
West	296 (21.3%)	50 (13.3%)	105 (21.5%)	451 (20.0%)
<b>Annual Medicare Volume</b>				
< 25 Patients	61 (5.0%)	53 (15.7%)	123 (29.4%)	237 (11.9%)
25 - 49 Patients	98 (8.0%)	72 (21.4%)	105 (25.1%)	275 (13.8%)
50 - 75 Patients	103 (8.4%)	71 (21.1%)	71 (17.0%)	245 (12.3%)
≥ 75 Patients	970 (78.7%)	141 (41.8%)	119 (28.5%)	1,230 (61.9%)

Source: Virnig et. al., 2002.

<sup>1</sup>A metropolitan county that contains a city with a population of at least 50,000 or an urbanized area of at least 50,000 with a total metropolitan population of at least 100,000.

<sup>2</sup>A non-metropolitan county that is located physically adjacent to one or more metropolitan counties.

<sup>3</sup>A non-metropolitan county that is not located physically adjacent to a metropolitan county.

sites) (Table 2). Two sites were selected in states with high hospice use rates (Florida and Oregon) and two sites in states with hospice use rates near the national average (Minnesota and Wisconsin/Michigan).

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), as well as the collection of written materials and secondary data relevant to each site. A total of 64 interviews were conducted for the four hospices; three of these interviews were conducted by phone, and the rest in person. At each hospice, interviews were conducted with key hospice management and staff, including the hospice director, the medical director, the patient care coordinator/nursing supervisor, the social work director, the coordinator of volunteer services, the hospice chaplain, and hospice nurses.

In addition to hospice management in the main offices, team managers and staff at two satellite sites in Florida, and team coordinators from two satellite sites in Wisconsin, were also interviewed. Physicians, administrators, and staff at health care facilities who work with the hospice, including hospitals and nursing homes, were interviewed in each community.

Additional interviews were conducted with a hospice patient and family members of current or previous hospice patients at three sites; hospice board members at two sites; home health aides at two sites; and a hospice volunteer at one site. Semi-structured interview protocols were used to guide the interviews. Interview topics included the following:

- Background and history of the hospice
- Hospice organizational structure and staffing
- Hospice services and service area
- Characteristics of hospice patients served
- Referral process for hospice services
- Utilization measures
- Quality of care
- Relationship between hospice program and other health care providers in the community, including community physicians, hospitals, and nursing homes
- Budget and financial issues
- Reimbursement and regulatory issues
- Opportunities and challenges to providing hospice services in rural areas
- Lessons learned

Written summaries were prepared for each interview, and these interview summaries were then analyzed, and used to prepare a draft case study, following a case study outline format. Each participating hospice was given an opportunity to review their draft case study, and suggest changes prior to their inclusion in this report.

**Table 2**

**Organizational Characteristics of Rural Hospice Case Study Sites**

<b>Hospice and Location</b>	<b>Date Established</b>	<b>Medicare Certified</b>	<b>Organizational Structure and Ownership</b>	<b>Service Area</b>	<b>Number of Patients</b>
Kanabec County Public Health Hospice, Mora, MN	1998	1999	Rural, government-owned (county public health department), home health agency based	One rural county, population 14,996, land area 525 square miles, population density 28.6; serves patients within 30 miles one way in county	20 patients in 2000
Regional Hospice Services, Inc., Ashland, WI and satellite sites in Hayward, WI, Spooner, WI, and Ironwood, MI	1991	1992	Rural-based, not-for-profit, freestanding agency with four rural sites, sponsored by four community hospitals	13 rural counties and one urban county, population 291,396, land area 14,961 square miles, population density 19.5; serves patients within 50 miles one way	193 patients in 2000
Hospice of North Central Florida, Gainesville, FL and satellite sites in Chiefland, Lake City, Palatka, and Jacksonville, FL	1978	1985	Urban-based, not-for-profit, freestanding agency with three rural satellite sites, 18 bed inpatient and residential hospice center, adding home health services and DME at each site	5 urban and 11 rural counties, population 1,625,078, land area 10,064 square miles, population density 161.5; serves patients within 60 miles one way	2,281 patients in 2001 (1,295 rural and 986 urban)
Lower Columbia Hospice, Astoria, OR	1981	1991	Rural hospital-based not-for-profit, administered and staffed in part jointly with home health program, 5 bed residential hospice center	One rural county, population 35,630, land area 827 square miles, population density 43.1; serves patients within one hour driving time.	129 patients in 2001

## **CASE STUDIES**

This section describes the results of our site visits from September 2001 to April 2002 to four hospices that provide services in rural areas. Kanabec County Public Health Hospice in Mora, Minnesota, which was established in 1998 and served 20 patients in 2000, was the youngest and the smallest hospice we visited. It is based in a home health agency that is part of the county public health department. The Lower Columbia Hospice in Astoria, Oregon, is a hospital-based hospice program that provides hospice services in rural Clatsop County. Established in 1981 as a volunteer program, the hospice was Medicare certified in 1991 and served 129 patients in 2001. Regional Hospice Services, based in Ashland, Wisconsin, is a freestanding agency that provides hospice services in a large, sparsely populated rural area of northern Wisconsin and the Upper Peninsula of Michigan. With four rural sites, it served 193 patients in 2000. Hospice of North Central Florida, based in Gainesville, Florida, is a very large, freestanding regional model hospice that provides hospice services in a 16 county rural and urban area of north central Florida. It started in 1978 as a volunteer program, was Medicare certified in 1985, and served a total 2,281 patients, including 1,295 rural patients, in 2001.

### **Kanabec County Public Health Hospice (Mora, MN)**

#### ***Background and History of the Hospice***

The Kanabec County Public Health Hospice is located in Mora, MN, a rural community of 3,193 persons, located about 70 miles north of the Twin Cities metropolitan area. Mora is the county seat and largest population center in Kanabec County.

The hospice is based in the Kanabec County Public Health Agency. It operates in conjunction with the agency's home health program, including sharing staff. Besides hospice and home health services, the agency also provides maternal and child health, disease prevention and control, health promotion, and environmental health services. Agency services are paid for by a variety of public and private insurance sources, grants, donations and sliding scale fees based on ability to pay.

The Kanabec County Public Health Agency has been providing home care services since 1972, and is the only home health agency in the county. The hospice program started in 1998 and received Medicare certification in 1999. An Advisory Committee, which included representatives from the public health agency, the hospital, and the community, guided the initial development of the hospice. Committee members agreed that there was a need to provide hospice services locally, and that the public health agency was in the best position to develop a hospice program. The agency used a federal Title III grant to help fund the hospice program in the first year of operation before it became Medicare certified.

The mission of the hospice program is “to provide quality medical, emotional, and spiritual care to people as they near the end of life’s journey.” The agency sees the provision of hospice care as consistent with its overall mission to take care of the health needs of the county. Prior to the establishment of the hospice program, the agency was providing some “hospice-like” services to home care patients.

In addition to the hospice/home health care agency, the local health care system in Mora includes a 49 bed JCAHO accredited hospital, Kanabec Hospital, an 80 bed dually certified skilled nursing facility, Villa Health Care Center, and a clinic, Allina Medical Clinic-Mora, staffed by eight family physicians, an internist, an allergist, three orthopedic surgeons, one physician assistant and two nurse practitioners. Specialists from the Twin Cities, including an oncologist, visit the community on a regularly scheduled basis. The hospice Medical Director estimates that about 30 to 40% of Kanabec County residents obtain medical care outside the county, primarily in Cambridge (28 miles away), the Twin Cities, or the Veterans Administration facility in St. Cloud (45 miles away).

### *Hospice Services and Service Area*

The hospice provides all services required by the Medicare program, including nursing and home health visits; medications, medical supplies and equipment; social work and chaplain services; trained hospice volunteers who offer respite and support to patients and families; short-term hospitalization for symptoms that are unmanageable at home; in-patient respite care to relieve caregivers; and year-long bereavement support for family members. Hospice services are primarily provided in patients’ homes, and have also been provided to a few patients in the local nursing home. The local hospital has a special hospice room for occasional use by hospice patients who need inpatient care.

Kanabec County is the service area for all of the public health agency’s services, including hospice care (Table 3). The county covers 525 square miles. According to the 2000 Census, the total county population was 14,996, and is predominantly white (97.3%). Median household income in the county (\$31,555 in 1997) is considerably lower than the state (\$41,951). The proportions of the county population over age 65 (14.1%) and below the poverty level (12.5%) are also higher than the state averages.

Many of the hospice’s patients have lived in Mora. Staff travel as far as 30 miles one way, within the county, to a patient’s home. The agency has had people move into the county, for example, with their adult children, to obtain needed hospice services.

### *Hospice Organization and Staffing*

The director of the Kanabec County Public Health Agency oversees all of the agency’s programs, including the hospice program. Hospice program staff include the home care nursing

supervisor, six nurses, the home health aide supervisor, 17 home health aides, the medical director, hospice social worker, and chaplain. The hospice currently has 15 volunteers.

**Table 3**

**Population Characteristics of Kanabec County  
Public Health Hospice Service Area**

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Population (2000)	14,996
Persons/sq mile (2000)	28.6
Population 65+ (2000)	14.1%
Race/Ethnicity	
White	97.3%
Black	0.2%
American Indian	0.8%
Asian	0.4%
Hispanic/Latino	0.9%
Percent below federal poverty line (1997 estimate)	12.5%
Medicare decedents (1999)	89
Medicare hospice use rate (1999)	12.4%

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Sources: US Census 2000; CMS Medicare Hospice File 1999 and Denominator File 1999; Area Resource File 1999.

The home care nursing supervisor is an RN who formerly worked as a home care nurse in the agency. She supervises five RNs and one LPN who provide hospice and home health care nursing services. The RNs work in designated geographic areas within the county, and the LPN does caseload sharing with all the RNs. All the nurses share the 24 hours a day/7 days a week on call coverage for the hospice program.

Home health aides also care for both hospice and home health patients, providing assistance with personal care needs such as bathing and dressing, home management needs, meal preparation, and light housekeeping. About half of hospice patients use home health aides, which helps to prevent primary caregiver burnout. The hospice medical director is a family practice physician at the local clinic. He provides medical direction to the hospice team, and facilitates communication between hospice staff and physicians in the community.

The part time hospice social worker works with patients and families on death and dying issues, and mental health concerns such as anxiety, depression, and denial. She also coordinates the hospice volunteer program. Hospice volunteers provide a variety of services, including companionship, respite for the family, light housekeeping, meal preparation, errands, and bereavement support. Volunteer training involves four 3-hour sessions that cover 1) introduction to hospice and concepts of death, dying, and grief; 2) communication skills, care and comfort measures, and understanding diseases and conditions; 3) psychosocial and spiritual dynamics of death and dying, and the hospice family; and 4) understanding the bereavement process, managing personal stress, and Kanabec County Resources. The hospice benefits from having a large enough number of volunteers so that patient needs and volunteer skills and interests can be matched well. Volunteers also participate in fund-raising efforts for the hospice.

The chaplain provides spiritual services to hospice patients who do not have their own pastor, and request to see him. He visits patients in their homes or in the nursing home periodically, unless there is an immediate need, then he sees them right away. The chaplain also participates in hospice team meetings and training of volunteers. Because the hospice program is small and funds are limited, the chaplain is a volunteer who receives no salary. Consequently, he is balancing the needs of the hospice program with those of his own congregation.

The hospice is currently fully staffed. Flexible scheduling helps with staff retention, and the agency has not had much turnover in its nursing positions. It has, however, experienced the effects of the nursing shortage when it has recruited, receiving a limited number of applicants for some vacant positions. Most nurses at the agency are originally from the area, and were educated in the Twin Cities. Staff training for the hospice nurses is primarily on the job training; nurses also participate in educational programs offered at the local hospital. The part time hospice social worker position has experienced a lot of turnover. The medical director and chaplain have been with the hospice program since it began.

Hospice team meetings are held every other week to conduct case by case reviews of patient care and family needs. The home care nursing supervisor, nurses, medical director, chaplain, and family members participate in team meetings. The home care supervisor also meets with the nurses every week. The hospice conducts a written satisfaction survey at least once while the patient is receiving care, and tries to do it every six months, if the patient lives longer than six months. The survey is addressed directly to the hospice patient; sometimes the families take part, and other times they do not.

### ***Hospice Patients***

The Kanabec County Public Health Hospice served eight patients in 1998 and seven patients in 1999, its first two years of operation. In 2000, the program had 20 hospice patients, who received a total of 329 nursing/case management visits and 294 home health aide/homemaker visits. As of September 2001, the hospice census was three patients, which was

below its “ideal” census of about five patients. The agency has served as many as nine hospice patients at one time, and has never had to turn patients away because of reaching capacity.

Most hospice patients have been older adults; the hospice has also served middle-aged adults, and would serve younger patients if asked to. In 2000, 14 out of the 20 hospice patients were cancer patients. The rest had a variety of diseases, including degenerative neuromuscular disease, renal failure, cirrhosis, and congestive heart failure. In 2001, all patients except one had cancer. The focus of symptom management for cancer patients is on pain medications, and dealing with nausea and constipation; with respiratory diseases, the focus is on oxygen use, anxiety and restlessness.

In 2000, 15 hospice patients were covered by Medicare, two by Medicaid, and three by private insurance. The 2001 caseload was primarily Medicare. The hospice currently has a patient without any insurance; the county will absorb the costs of serving this patient. In the first year of operation, the average length of stay for hospice was 35 days. In 2000, the ALOS was 73.3 days, and the median was 111.5 days. The increase in ALOS may reflect a decline in late referrals, as physicians and community members became more aware of the benefits of the hospice program.

Hospice patients find out about the availability of hospice in Kanabec County in several ways. The hospice program gets referrals from physicians, families, and friends. They distribute information about home care and hospice at the clinic and at hospitals in the Twin Cities where county residents are hospitalized. They also advertise in the local newspaper and church bulletins, and use fundraisers and the American Cancer Society Relay for Life to focus attention on hospice.

Hospice and hospital nursing staff agree that only a small portion of patients in the community who could benefit from hospice care are currently receiving it, for a variety of reasons, including reluctance on the part of some patients, families, and physicians. Some patients and families have a hard time accepting a terminal diagnosis, especially patients with respiratory and other non-cancer illnesses who may experience “peaks and valleys” in their condition rather than steady deterioration. Hospice staff note that they have had dying home health care patients whose physician didn’t tell them about the progress of their disease. Some physicians do not want patients, especially younger patients in their 50s, to feel they have given up hope.

In some cases, patients do not obtain hospice care because they are receiving chemotherapy and radiation treatments until the end. While hospice patients could receive such treatments, the costs of providing them are prohibitive for the agency. Since the hospice program began, only one prospective hospice patient has wanted to receive chemotherapy. The hospice offered to refer this patient to a Twin Cities area hospice that provides chemotherapy, but the patient chose not to do this.

In the future, the hospice expects to have more patients in general, and some younger patients, as community members become more aware of the hospice program, and physicians become more comfortable referring patients. The program does not anticipate any difficulty serving more patients; the agency has some flexibility in staffing because its nurses provide both hospice and home health care services.

### ***Relationship between the Hospice Program and Other Health Providers in the Community***

Hospice referrals and coordination of patient care across health care settings depend to a large extent on the nature of the relationships between the hospice program and other health care providers in the community. Hospice relationships with community physicians are critical, since physicians are responsible for the vast majority of hospice referrals, and, in most cases, maintain a physician-patient relationship with their patients who receive hospice care. Relationships with hospitals are also important, since they provide inpatient care when needed for hospice patients, and to ensure coordination when patients are transferred from inpatient to hospice care. Hospital nurses also often assist with hospice referrals by providing patients and families with information about hospice care. Hospices also need to work with nursing homes and home health agencies to obtain referrals to hospice care when appropriate, and to coordinate the provision of hospice care in nursing home settings.

#### Physicians

Overall, hospice and hospital nursing staff in Mora describe community physicians as supportive of hospice and open to considering hospice as an option for their patients. Some physicians make more referrals to hospice than others; most referrals come from three physicians in the community, including the Medical Director. Delays in referrals to hospice have been a problem in some cases. Sometimes the oncologist and community physicians have differences of opinion about whether to keep treating cancer patients aggressively. Establishment of a prognosis can be a difficult task for physicians, and some physicians are reluctant to say that a patient only has a certain amount of time to live. Pain management for hospice patients is an issue with some physicians; they want to “save the big stuff until the end,” not realizing or accepting that it is the end for a patient with only a few months to live.

#### Hospital

The Kanabec Hospital offers a range of inpatient and outpatient services based on community needs, including chemotherapy for cancer patients. In addition to its contract with the Kanabec County Public Health Hospice, the hospital also has contracts with the hospice in Cambridge, and the Allina Hospice in the Twin Cities. However, most hospice patients are cared for by the county hospice. 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 in order 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 in patients' homes. The relationship between the county-owned hospital and the hospice is described by staff of both entities as good.

The hospice and hospital have worked out a procedure so that hospice patients can be admitted directly to the hospital's hospice room, without having to go through the emergency department, for conditions related to their terminal illness. Hospice patients who are hospitalized for conditions not related to their terminal illness are treated as general patients. The hospice has a plan of care to the hospital within 12 hours for hospice patients who are hospitalized. Their hospice primary nurse coordinates the patient's care with the hospital charge nurse; hospice staff also work with the on call physicians, the social workers, and, as needed, with the chemotherapy nurse regarding pain symptoms and management. Under the contract with the hospital, the hospice provides the medications that patients are taking, unless it is a medication the patient wasn't taking prior to admission or the hospice doesn't have.

### Nursing Home

The relationship between the hospice and the nursing home is relatively new, and appears to still be evolving. Two hospice patients resided at the nursing home in 2000; both had been receiving hospice care at home, and moved to the nursing home when they no longer had a primary caregiver able to care for them at home. The hospice currently has one patient at the nursing home. The hospice nurse works primarily with the nursing home charge nurse.

Nursing home staff view the benefit of hospice as providing support to the family and the patient. From their perspective, the hospice and the nursing home have comparable abilities to control pain, and the hospice presence does not help relieve nursing home staff issues. The nursing home's primary concern is communication regarding responsibility for patients. The nursing home staff now go through the hospice nurse rather than directly to the physician for changes in pain management medications. The nursing home recently began having the hospice nurse chart in the nursing home charts, to ensure documentation of communication between staff from the two organizations. Since the hospice nurse who is currently working with the nursing home staff previously worked at the nursing home, she knows the staff and how the nursing home works, which is helpful. Every other hospice team meeting is held at the nursing home, to encourage participation of nursing home staff.

### ***Budget and Financial Issues***

The total budget for the Kanabec County Public Health Agency was \$1.27 million in 2000. Home care (including home health and hospice care) revenues accounted for 32 percent of agency revenues. County tax dollars accounted for 18.5 percent of total revenues, and the agency director actively pursues grants to help address budget shortfalls.

The 2000 budget for the hospice program was \$72,000. Medicare funding accounted for a large portion of the hospice budget; there was also some Medicaid funding, and about \$10,000 came from donations. The hospice program usually breaks even on patients with insurance but it has had patients without any insurance. Shortfalls in the hospice budget are subsidized by the county, which has been very supportive of the hospice program.

### ***Reimbursement and Regulatory Issues***

As of September 2001, the hospice program was receiving a Medicare per diem rate for routine hospice care at home of about \$100 a day. The high cost of pain medications is the hospice's main challenge right now. One of the hospice's current patients is receiving pain medications that cost \$3,000 a month, which uses up the hospice's entire per diem payment, leaving the hospice to absorb the costs of nursing care and all other care provided to the patient. Hospice staff believe strongly that it is important to manage patients' pain, because the patient's quality of life is so much better if you can do that.

One problem the hospice program had with the Medicare certification process was obtaining approval from the federal Office of Civil Rights. (Their previous approval for home health certification was done almost 30 years earlier and was outdated.) The agency was required to show that it was serving minority populations, which was difficult given that the population of Kanabec County is over 97% white.

### ***Opportunities and Challenges to Providing Hospice Services in Rural Areas***

The small volume of patients in the Kanabec County hospice program (20 hospice patients in 2000) allows the home care supervisor to be individually involved with each hospice patient, and available for questions and concerns. However, the small volume makes it very difficult for the hospice to spread the risk of one or two patients who are high cost because they need expensive medication, or lack insurance coverage for hospice services.

A low volume of hospice patients also creates challenges for staffing. The Kanabec County Public Health Agency has addressed this challenge by operating the hospice program in conjunction with its much larger home health program, which served 345 patients in 2000. Nurses usually have one or two hospice patients in their caseloads, along with several home health patients. This variety helps prevent burnout of nurses, spreads the responsibility for hospice on-call coverage over several nurses, and allows caseloads to be assigned to some degree geographically within the county.

Both urban and rural hospices must cover travel costs, including staff time and mileage reimbursement, but the Medicare hospice per diem payment does not make any allowances for rural hospices that incur large travel expenses serving patients who live at a significant distance from the hospice. Rural areas are also not immune from safety concerns for their staff. Kanabec

County serves a number of high risk families, and the hospice has had situations where it was necessary to send two staff members to a patient's home when it was not safe to send one alone.

Coordination between the hospice and other local health care providers is simplified by the fact that there is only one physician group practice, one hospital and one nursing home in the community. However, a significant portion of local residents are receiving health care in other communities, which makes it more difficult for the hospice to coordinate their care. The medical director of the hospice has more responsibility for hospice patients who are getting care in another community.

In rural communities where "everybody knows everybody else," hospice staff are likely to know many patients and their family members personally. This familiarity can be positive, for example, by allowing a hospice nurse to talk honestly with family members she has known for a long time about a patient's prognosis, or it can be awkward, depending on the situation. Kanabec County Public Health Hospice nurses try not to be the primary care nurse for their friends. Hospice patients may request a particular nurse, and may ask to change nurses if it is not a good match.

The sharing of information among neighbors or friends about experiences with hospice care can help increase knowledge about hospice care in a small community, and break down some of the barriers to dealing with end-of-life issues. Having a hospice program in Kanabec County is changing attitudes about certain diseases and deaths, not only for the families who are directly involved, but also through a spin off effect on others.

### ***Lessons Learned***

Analysis of the information gathered during our site visit to the Kanabec County Hospice generated several important insights into the provision of hospice care in this rural setting, which are summarized below.

- Coordination of care for hospice patients across agencies may be easier in a rural community with a small number of health care providers. At the same time, however, a rural community that is adjacent to a large metropolitan area may have a significant portion of residents who obtain medical care outside the community. This situation makes it more difficult for hospice nursing staff to communicate with patients' physicians and other health care providers, and places more responsibility for medical supervision on the hospice medical director.
- The decision about where to locate a rural hospice program (e.g., in a public health agency, hospital, or freestanding) depends on several factors. Community trust in the organization selected and agreement among providers about the decision are important. In this case, the public health agency was a logical choice, because it had a longstanding home health

program, with a committed nursing staff that was experienced in caring for people at home. It also had a good working relationship with the hospital, which agreed that the public health agency should provide the service.

- A low volume of patients creates financial challenges for rural hospices. A rural hospice program with a small number of patients will have financial difficulty spreading the risk of high cost patients, for example, patients with large drug expenditures, and covering costs for uninsured patients. It is likely to need financial support to survive, including donations and, in the case of a public agency, support from a county board or other public entity.
- Low patient volume, fluctuating census levels, and significant travel distances create staffing challenges for rural hospices. Joint staffing of a small hospice program and a larger home health program allows hiring of full time staff with benefits, who care for mixed caseloads of hospice and home health patients. This can help an agency deal with fluctuations in hospice census and reduce staff travel. It can also help prevent staff burnout by providing variety in patient caseloads and spreading responsibility for on-call coverage over a larger number of staff.

### **Lower Columbia Hospice (Astoria, OR)**

#### ***Background and History of the Hospice***

The Lower Columbia Hospice (LCH) is a hospital-based hospice program that provides hospice services throughout rural Clatsop County on the Pacific Coast of Oregon. The hospice is located in Astoria (population 9,813), about 100 miles from Portland, Oregon and 50 miles across the Columbia River from Longview, Washington. The hospice is based in Columbia Memorial Hospital (CMH), a 49 bed hospital that had 2,396 admissions in 1999.

The mission of LCH is “to assist the patient and family in maintaining quality of life during a terminal illness. The hospice team strives to support the patient and family toward coping with illness and death. Our goal is to provide comfort and pain control.”

The Lower Columbia Hospice program began in 1981. An oncology nurse at CMH became interested in hospice care and did the initial organizational work to establish the hospice program. CMH nurses worked with nursing staff from the Clatsop County Public Health Department, which at that time was providing home health services in the county, to provide hospice services. The hospice program operated for ten years as a volunteer program, with a community advisory board. With the encouragement of the current CEO of CMH, the hospice applied for and obtained Medicare certification in 1991.

In addition to providing care in patients’ homes, LCH operates a Hospice Adult Foster Home, a five bed residential facility for hospice patients who do not have a caregiver at home or

who need more care than their primary caregiver can provide. The house was willed to LCH as part of a deceased hospice patient's estate, was extensively remodeled, and opened as a licensed adult foster home for hospice patients in February 1999. It is located in Warrenton, a short distance from Astoria.

The Lower Columbia Hospice is the only hospice program in Clatsop County. In addition to Columbia Memorial Hospital, the health care system in Clatsop County includes 34 bed Providence-Seaside Hospital in Seaside (population 5,900), which is about 17 miles from Astoria, and three dually certified skilled nursing facilities. The two nursing facilities in Astoria, 73 bed Clatsop Bridges Care Center and 45 bed Clatsop Care Center, and an assisted living facility in Astoria are owned by a not-for-profit health district. Providence-Seaside Hospital has a 22 bed SNF. Both hospitals have home health programs; CMH's home health program was initiated in 1994, when the County Public Health Department closed their home health program.

Astoria has several small primary care practices. The medical staff of CMH includes five family physicians, six internists, three pediatricians, and two Ob/Gyns, as well as several specialists. In addition, consulting specialists from the Portland and Longview areas are also on the CMH Medical Staff. Seaside has two primary care practices, with seven family physicians, two internists, and an Ob/Gyn on the Providence-Seaside medical staff. Access to primary care in the Astoria area has been up and down over the past few years. In Fall 2001, the closure of an Astoria practice sponsored by the hospital in Longview resulted in the loss of four family physicians and one Ob/Gyn. Some primary care practices in Astoria are now closed to new patients.

### *Hospice Services and Service Area*

Like other Medicare-certified hospices, LCH provides all the hospice-related services required by the Medicare program, including nursing and home health visits; medications, medical supplies and equipment; social work, chaplain and volunteer services. The hospice sponsors a loss and separation support group that meets twice a month at the hospital. The group is run by the hospice social worker, and is open to the public as well as hospice family members. The hospice recently began sponsoring a special bereavement program for children throughout Clatsop County. Support groups for children will be offered through the local office of Lutheran Community Services NW.

Hospice services are provided primarily in patients' homes and the Hospice Adult Foster Care Home; they are also provided to a few patients in local nursing homes. Hospice patients who need inpatient care or respite care are hospitalized at Columbia Memorial or Providence-Seaside hospitals. CMH has one room, with an adjoining family room, that it tries to keep open for hospice patients who are hospitalized unless the hospital census is very high.

The service area for LCH is Clatsop County, which covers 827 square miles, and has a population of 35,630 (Table 5). The official service area for the hospice is a 45 minute radius from Astoria, but hospice staff often travel up to an hour one way to a patient's home. The next nearest hospices are about a half hour north in Ilwaco, Washington, one hour northeast in Longview, WA and 1½ hours south in Tillamook, OR. As of 2000, Clatsop County had higher proportions of population over age 65 (15.6%) and below poverty (13.3%) than the state of Oregon. The county population is predominantly white non-Hispanic (93%).

**Table 5**

**Population Characteristics of Lower Columbia Hospice Service Area  
(Clatsop County)**

Population (2000)	35,630
Persons/sq mile (2000)	43.1
Population 65+ (2000)	15.6%
Race/Ethnicity	93.1%
White	1.2%
Asian	1.0%
American Indian	4.5%
Percent below federal poverty line (1997 estimate)	13.3%
Medicare descendents (1999)	309
Medicare hospice use rate (1999)	26.2%

Sources: US Census 2000; CMS Medicare Hospice File and Denominator File 1999; Area Resource File 1999.

***Hospice Organization and Staffing***

LCH has a nine member Advisory Board, which is appointed by the CMH Board. The Board focuses mainly on fundraising and education regarding hospice in the community, and is responsible for funds willed and donated to the hospice program. The full board meets every other month; the Finance & Fundraising and Education & Community Awareness subcommittees also meet alternate months, when the full board does not meet.

All of the hospice staff are CMH employees, and receive the same salaries and benefits as comparable positions in the hospital. The manager of the hospice program also directs CMH's home health program, and the LCH Adult Foster Home. Other administrative staff and home health aides are shared between the hospice and home health programs, while the nursing staff for the two programs is separate.

The hospice nursing staff includes an RN patient care coordinator, who works 4 or 5 days per week; four staff nurses, who each usually work 2½ days per week; and one relief nurse. The

RN patient care coordinator is the initial point of contact for prospective hospice patients and families, providing information about the hospice philosophy and available services. For hospice patients, she arranges for nursing, home health, social work, chaplain and volunteer services, and communicates with the patient's physician about symptom control. One of the staff nurses fills in for the patient care coordinator as needed, works with the hospice staff to prepare for JCAHO accreditation, coordinates the hospice volunteer program, and organizes fundraising activities.

The staff nurses are guaranteed 20 hours a week of work, and may work additional hours if the hospice census is high. All of the nurses, including the patient care coordinator, take turns covering call, from 4 PM to 8 AM on weekdays, and one weekend a month. Two full-time home health aides provide personal care and light housekeeping assistance for hospice and home health patients.

The hospice medical director is a semi-retired internist, who works about 50% time in his private practice. He has had a long term interest in hospice, and is board certified in hospice and palliative care. He became the Medical Director of the hospice in 1995. As Medical Director, his responsibilities include participating in weekly care planning conferences with the hospice staff, and conferring with hospice nurses regarding medications and dosages if they are unable to reach a patient's own physician (he is available by pager 24 hours a day). He also cares for 1-2 patients at a time who enter hospice care without a primary care physician in the area; sees patients at home at the request of the hospice nurses or the patient's own physician; and provides community physicians with current information about hospice and pain medications through a quarterly newsletter and speaking at medical staff meetings.

The medical social worker works about 25% to 30% time in hospice, and also has a private practice. She is the social worker for the home health program as well, but does not see many home health patients; the home health census has declined with implementation of PPS, and nurses do some referrals to community resources for home health patients. For all hospice patients, the social worker does an initial patient and family psychosocial assessment at the patient's home or at the LCH Adult Foster Home. Follow-up visits are scheduled depending on need, and if there is a change in the patient's status.

The hospice chaplain is also the CMH chaplain. He works approximately 25 hours per week, and spends about half of his time with hospice patients, unless the hospital has a full census and he is needed there. The hospice chaplain acts as a liaison for hospice patients who have their own clergy, and serves as chaplain for patients who do not have their own clergy and request his services. He visits hospice patients and families at home, in the LCH Adult Foster Home, and in nursing homes, and does memorial services by request.

LCH currently has 18 hospice volunteers. Volunteer training is conducted once a year, usually for about 4 to 6 people. The training takes about 25 to 30 hours. All of the hospice staff

participate in the training, so that hospice staff and volunteers get to know each other. The hospice tries to match volunteers with their interests; some volunteers provide services to patients and families at home or in the LCH Adult Foster Home, while others work in the hospice office or focus on fundraising activities. Local high school students also volunteer through their leadership classes. The students do non-patient care activities under supervision at the LCH Adult Foster Home, for example, helping outside with yardwork. Students have also done their own fundraising for the hospice program.

The hospice manager, RN patient coordinator, the staff nurses, the medical director, the social worker, and the chaplain have hospice team meetings every week, to discuss patients' symptoms and pain medications, their care situation at home, and the need for additional services. Family members and patients' physicians are also invited to the team meetings, and sometimes come.

LCH hospice has not had a lot of turnover in administrative or nursing staff. The hospice director, patient care coordinator, medical director, and social worker have all been with the program for several years, and one staff nurse has worked in the hospice program for 20 years. Nursing staff are mainly recruited by word of mouth. The hospice nurses often recruit other nurses with whom they have worked in the hospital, and one of the home health aides also worked for the hospital previously. The hospice manager has found that having hospice nurses work less than full time allows them to balance their work and family life, and providing some flexibility in scheduling reduces staff turnover.

A staff person is on duty at the LCH Adult Foster Home 24 hours a day. LCH initially tried staffing the house with a resident caregiver, but the burden of providing 24 hour care was too much for one person, since hospice patients are sometimes awake a lot at night. Therefore, LCH obtained a waiver from the State of Oregon Senior and Disability Services Office, which licenses adult foster homes, to have shift caregivers. The LCH Adult Foster Home currently has a manager and six staff who work rotating 8 to 12 hour shifts, 3 to 4 shifts per week. The manager is in the process of completing her RN degree; some of the staff are certified nursing assistants, and others had prior experience providing home care. Staff receive training in providing medications, and personal care. They give patients medications according to schedule, bathe patients, provide meals, and generally provide TLC to patients and support to families. In addition to hospice nursing visits to patients, staff at the LCH Adult Foster Home have phone access to hospice nurses 24 hours a day/7 days a week.

### ***Hospice Patients***

To be eligible for hospice services, a patient must live in Clatsop County; be under the care of a physician with practice privileges at Columbia Memorial Hospital or Providence Seaside Hospital; have a life expectancy expressed in months not years; and have decided that "active treatment of illness is completed, unwanted, or not beneficial."

LCH served a total of 129 hospice patients in 2001, including 34 patients cared for at the LCH Adult Foster Home. In early 2002, the hospice census was 12-13 patients, which is lower than the hospice's ideal census of about 18-20 patients. LCH has never turned away hospice patients because of reaching capacity. When the census has increased, LCH has had current staff work additional hours, including having home health staff help with hospice patients, and then added additional hospice staff.

The majority of LCH patients have cancer diagnoses, although the proportion of patients with other diseases, notably chronic obstructive pulmonary disease and congestive heart failure, is increasing. Medicare beneficiaries comprised 94% of LCH patients in 2000, and 83% in 2001. Most other patients are in their 40s or 50s, but the hospice has also served younger patients, including infants. The only problem LCH has experienced in caring for non-elderly patients has been that some younger people in the area have their health insurance through Kaiser Permanente. Kaiser tells its enrollees that LCH is out of Kaiser's service area, and that their options are to use Kaiser's facilities, which are a minimum of one hour away, or pay out-of-pocket for their hospice care.

In 2001, LCH had a total of 5,023 patient days, and an average length of stay of 38.9 days. The length of stay at The LCH Adult Foster Home averaged 28.5 days in 2001. The hospice manager estimates that at least 50% of Clatsop County residents who die and would be eligible for hospice receive hospice services from LCH. However, even though LCH is hospital-based and the only hospice serving the area, it can not necessarily count on receiving referrals of all CMH patients who would be eligible for hospice, because community physicians vary in their willingness to refer patients to hospice care, and some patients continue treatments until death.

LCH does not provide radiation or chemotherapy to hospice patients. Radiation therapy is not available at CMH at all; patients from the area go to hospitals in Longview, WA or Portland for radiation. CMH has a small chemotherapy program for established patients, but many cancer patients go to Longview or Portland for chemotherapy. It would be difficult financially for LCH to cover the costs of radiation and chemotherapy for hospice patients.

Hospice patients and families primarily find out about LCH through word of mouth, from friends, neighbors, or family members who have used hospice. A print ad campaign has increased knowledge about the hospice. The hospice's annual fundraiser, a picnic and auction, is well-publicized in the community, and was attended by over 600 people in 2001. The LCH Adult Foster Home has increased the visibility of the hospice program in the community. The hospice manager and hospice board members also give educational talks to community groups about the hospice program and end-of-life issues.

LCH conducts patient/family satisfaction surveys throughout the year and after each patient's death. The survey used is based on one from the National Hospice Organization, with

the addition of a section relating to satisfaction with volunteer services. The hospice has a quality management plan and is JCAHO accredited.

During our site visit, family members of a deceased hospice patient described the hospice staff as thoughtful and compassionate in their work with the patient and family. The elderly spouse had been exhausted by 24 hour caregiving responsibilities, but was unwilling to place the patient in a nursing home. He was very satisfied with the care provided by the hospice, and appreciated extra things that the staff had done for them, for example, providing special meals for the couple on their anniversary and Valentine's Day. Cost was a concern for the spouse, who had paid out of pocket for the care for four months, and was in the process of applying for financial assistance when the patient died.

### ***Relationship between the Hospice Program and Other Healthcare Providers in the Community***

#### Hospitals

According to hospice and hospital nursing staff, CMH administration is supportive of the hospice program. Relationships between the hospice program and hospital nursing staff are positive, and communication is good. Hospice patients are admitted to CMH for respite care, and for symptom management, if their symptoms can't be controlled at home. LCH conducts yearly in-services for CMH staff to increase their comfort level with hospice. The hospital nursing staff appreciate the hospice nurses' expertise with pain management, and request consultations for hospitalized patients when they need help regarding pain control.

LCH's hospital-based status has provided financial stability for the hospice. CMH subsidized LCH from its beginnings as a volunteer program until 2000, which was the first year that hospice reimbursement fully covered direct patient care expenses. The hospital continues to provide a financial base for the hospice program, e.g., assuring that the hospice is able to pay its bills on time. Another advantage of CMH's ownership of LCH is that the hospice staff are hospital employees. They receive the same salaries and benefits as other hospital employees, which facilitates recruitment and retention.

The hospice program has benefitted, both financially and in the ability to coordinate care, from using the CMH pharmacy for hospice patients' medications. The hospice has been paying the hospital pharmacy about 4% above costs for medications. Hospice staff have been very pleased with the hospital pharmacy services; they are able to consult with the hospital pharmacists on a regular basis, and obtain emergency medications on short notice. At the time of our site visit, however, in March 2002, LCH was planning to begin using a national direct delivery hospice pharmacy service for patient medications for a 90 day trial period. LCH anticipates that a switch to the mail order pharmacy will almost double its medication costs. The decision to try the mail order pharmacy was made because CMH pharmacists have been very

busy, as a result of the hospital's ongoing full census and increased emergency room use. The hospital has also experienced difficulty recruiting additional pharmacists, and recently had one of its 3 pharmacists recruited away to a larger facility. Following our visit, LCH began using the national pharmacy service in May, 2002.

At the time of our visit, the hospice program was located on the CMH campus, in a building directly behind the hospital. Shortly thereafter, LCH moved to a new location less than a mile away in downtown Astoria. Hospice and hospital staff do not expect the move to negatively affect the relationship between the hospice program and the hospital, and LCH hopes that the move may increase the general visibility of the hospice program in the community.

### Physicians

Hospice staff indicate that most Astoria physicians refer some patients for hospice care, a few physicians refer fairly often, and a few physicians either never refer patients for hospice care or only refer them in the last day or two of life. About half of LCH's referrals come from the Seaside area, which has a smaller population than Astoria, but has a few physicians who have been strong supporters of hospice care. A community physician who refers to LCH described the relationship between physicians and the hospice program as good, indicating that hospice nurses are accessible and responsive, and communicate well with physicians.

Late referrals are a concern for LCH. Sometimes the reason for the late referral is physician reluctance; patients are not given the option of hospice care earlier. In other cases, patients and families want to continue aggressive treatment until the end. Late referrals make it difficult for the hospice to get everything done that needs to be done, in terms of making the patient comfortable and getting their pain controlled. They are also a financial strain for the hospice, because the hospice per diem rate is based on average daily costs, and patients with short lengths of stay use comparatively much more resources. LCH has provided each community physician with a book about hospice care, and made presentations to physicians in hopes of getting earlier referrals. The hospice staff also relies on the medical director to work with physicians on referrals and pain control issues.

In a few cases, the transfer of patient care from oncologists in Portland to primary care physicians in Astoria has been problematic. Primary care physicians became upset when a few patients who they had referred to Portland were sent directly to the hospice after they refused chemotherapy, rather than being referred back to their primary care physician first.

### Nursing Homes and Assisted Living

The administrator of the two nursing homes and the assisted living facility in Astoria is familiar with hospice, having served on the LCH board for several years. LCH conducts in-services at the nursing homes about symptom control, and the nursing home administrator

regards the hospice as a resource to consult about pain control or unique family psychosocial situations. LCH has also had a contract with the nursing home in Seaside for several years. Over the past few years, LCH has had a few nursing home residents per year referred for hospice care; hospice referrals for assisted living residents are more common, numbering about 20 per year.

According to the Astoria administrator, additional nursing home referrals to LCH are limited for two reasons. First, the nursing homes don't have very many patients who die. Last year, the two nursing homes combined had 215 admissions and 31 discharges by death. Second, Medicare reimbursement does not cover the nursing home per diem for hospice patients, leaving patients to pay their nursing home per diems out of pocket if they are receiving hospice care.

### Home Health

LCH is aware of the financial pressures that home health agencies are facing as a result of PPS, since the CMH home health program has experienced a decline in patients and reduced its home health service area in response to PPS reimbursement changes. The only other home health program in the county, at the Seaside hospital, tends to make late referrals to LCH, which hospice staff think may be attributable to the Seaside program's need to keep their own patient load up.

### ***Budget and Financial Issues***

LCH maintains separate budgets for the hospice program and the LCH Adult Foster Home. In 2001, the hospice program, excluding the Foster Home, received reimbursement of approximately \$511,000; the vast majority of the reimbursement (93%) was from Medicare. Reimbursement exceeded direct patient care expenses by a small margin (\$8,503). The hospice's overhead allocation of 29%, which includes hospital-wide costs such as payroll administration, billing and purchasing, housekeeping, laundry, dietary, and data processing, was primarily absorbed by CMH.

In 2001, the LCH Adult Foster Home had expenses of approximately \$155,913, including depreciation. Net patient revenue, primarily from patient fees and Medicaid covered about 35% of expenses. Funding from the Hospice Advisory Board covered the deficit.

LCH receives a significant amount of financial and in-kind support from the community. Church-affiliated groups, community organizations, and local businesses contributed volunteer time and equipment to remodel the Foster Home, and provide ongoing support. Local rotary groups, for example, assisted with the purchase and installation of a backup electric generator for the home, and a heating supplier donates heating oil. Hospice fundraising activities generate \$75,000 to \$80,000 per year, including about \$50,000 from the annual auction and picnic, and \$25,000 to \$30,000 from donations and funds willed to the hospice. A majority of these funds

go to support the Foster Home. Some funding also goes to staff education; last year, for example, Hospice Advisory Board funds allowed five staff, including two hospital nurses, to attend a pain management workshop.

### ***Reimbursement and Regulatory Issues***

Like many other hospice programs, LCH relies on Medicare reimbursement for a large portion of its budget, so Medicare reimbursement and regulations have a significant influence on the hospice. LCH's average length of stay (ALOS) in 2001, 38.9 days, was significantly lower than the national ALOS of 48 days in 2000 and has decreased further in 2002 (NHPCO, 2002). The short ALOS is a financial hardship for the hospice, because Medicare's per diem reimbursement does not cover the resources it takes to care for a patient for only a few days. LCH would like the Medicare program to have a minimum payment for each hospice patient, to help cover costs for very short stay patients.

LCH's Medicare per diem rate for routine home care of \$114 as of March 2002 is not sufficient for the hospice to cover the costs of palliative chemotherapy and radiation for hospice patients. As a result, some patients who could benefit from hospice care may be unable to receive it, or receive it very late in the course of their illness.

A Medicare hospice regulation that has been a problem for LCH is the requirement that a facility have 24 hour RN care on site to provide respite care for hospice patients. The local nursing homes use LPNs on the night shift, so they can't provide respite care for hospice patients. Consequently, the only local option for respite care is hospitalization of the hospice patient.

LCH did not experience problems obtaining Medicare certification or JCAHO accreditation. Hospice staff stress the importance of preparing for accreditation all year long, by knowing the standards, and reviewing policies and procedures to make sure the standards are being met.

### ***Opportunities and Challenges to Providing Hospice Services in Rural Areas***

LCH's rural setting provides the hospice with opportunities as well as challenges. The hospice has positive, cooperative relationships with the majority of other health care providers in the county, facilitating coordination of patient care. Community support for the hospice is strong, and has enabled the Hospice Board to subsidize care at the LCH Adult Foster Home and pay for staff education. Hospice staff describe caring for hospice patients as rewarding and gratifying work.

The hospice also faces several challenges that are common to rural health care systems in general, and to rural hospices in particular. These challenges include maintaining an adequate

supply of primary care physicians in the community, especially physicians who are supportive of hospice care, and coordinating patient care with distant specialists. While LCH's volume of patients is larger than that of many rural hospices, it still requires financial support from the hospital, and can not cover the costs of expensive palliative treatments. Travel to patients' homes is a challenge in a large geographic area where a trip can take an hour one-way, and seasonal flooding occurs on some roads.

### *Lessons Learned*

The case study of Lower Columbia Hospice provided important lessons about the provision of hospice care in rural areas, using a hospital-based hospice model, and the impact of a supportive state environment for end-of-life care.

- This hospice's hospital-based status provides financial stability and facilitates recruitment and retention of hospice staff. The hospital administration is supportive of the hospice program, and relationships between hospice and hospital nursing staff are good. Nonetheless, being hospital-based does not necessarily translate into automatic referrals of hospice-eligible hospital patients. Community physicians' attitudes toward hospice are still a key factor influencing hospice referrals.
- In addition to providing care in patients' homes, this rural hospice successfully provides 24 hour care in a small, home-like environment for hospice patients who do not have a primary caregiver able to care for them at home. However, available reimbursement does not cover the cost of this type of care, so the LCH Adult Foster Home requires an ongoing financial subsidy.
- Oregon has a supportive environment for end-of-life care, as evidenced by the availability of hospice care in every county in the state, and one of the highest hospice use rates among Medicare beneficiaries in the country. State officials supported LCH's use of an adult foster care license to provide residential hospice services, granted a waiver to staff the home with multiple caregivers, and are interested in expanding use of adult foster care homes to provide hospice care.

### **Regional Hospice Services (Ashland, Hayward and Spooner, WI and Ironwood, MI)**

#### *Background and History of the Hospice*

Regional Hospice Services (RHS) is a freestanding agency that provides hospice services in a large, sparsely populated rural area of northern Wisconsin and the Upper Peninsula of Michigan. The main office of the hospice is in Ashland, WI, a rural community of 8,620 located on Lake Superior, about 70 miles from Duluth, MN. The hospice has three satellite sites in Hayward, WI (population 2,129), Spooner, WI (population 2,653), and Ironwood, MI

(population 6,293), and is currently discussing expansion to an additional site in Wisconsin.

The mission of RHS is “to provide individualized, compassionate, physical, spiritual, and psycho-social care and support to patients and families, enabling death with dignity as a completion of life.” Hospice services are paid for by a variety of public and private insurance sources, and donations. In addition, the hospice receives financial and in-kind support from the hospitals in the four communities where hospice sites are located: Memorial Medical Center in Ashland, Grand View Hospital in Ironwood, Hayward Memorial Hospital, and the Spooner Health System.

In 1987-88, Memorial Medical Center determined that there was an unmet need for hospice in Ashland, but that it was not financially feasible to operate a hospice program just in Ashland. The 96-bed Memorial Medical Center joined with 41-bed Hayward Memorial Hospital, which it owns, and 54-bed Grand View Hospital to establish a regional hospice program. The three hospitals agreed to put in \$30,000 in seed money, and to provide the hospice with space in each hospital at no charge. A hospice governing board was formed with representatives from each of the three communities. The hospice was incorporated as a not-for-profit organization, and became Medicare certified in 1992. Five years ago, the 46-bed hospital in Spooner joined in supporting the hospice program, and hospice services were expanded to Spooner.

In addition to the four hospitals, the local health care system in the four communities and nearby areas includes two nursing homes each in Ashland, Hayward, and Ironwood, and one in Spooner which is attached to the hospital. Some county public health agencies in the hospice service area provide home health services, including Bayfield, Sawyer, and Washburn Counties; Ashland also has a private home health agency, and the hospitals in Spooner and Ironwood own home health agencies. Ashland has three major primary care clinics: one owned by St. Mary’s Duluth Clinic, one by St. Luke’s Health Care System in Duluth, and one independent practice. Branches of the Duluth Clinic also operate in Hayward, Spooner and Ironwood. Consulting specialists from Duluth provide services in the area, for example, oncologists from Duluth see patients in Ashland every two weeks.

### ***Hospice Services and Service Area***

As a Medicare certified hospice, RHS provides all services required by the Medicare program, including nursing and home health visits; medications, medical supplies and equipment; and social work, chaplain, and volunteer services. Hospice patients who need short-term hospitalization for symptoms that are unmanageable at home or acute medical problems are hospitalized at one of the four community hospitals. Bereavement support groups and one-to-one support services are available throughout hospice care, and afterwards for family members. Hospice services are primarily provided in patients’ homes, and have also been provided to a few patients in local nursing homes.

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The service area for the hospice extends as far as 50 miles from each site, and includes eleven counties in Wisconsin and three counties in Upper Michigan (Table 4). The total

**Table 4**

**Population Characteristics of Counties in Regional Hospice Services' Service Area**

County	Population (2000)	Persons/ Sq. Mile (2000)	Population 65+ (2000)	Race		Population <Federal Poverty Line (1997 Est.)	Medicare Decedents 1999	Medicare Hospice Use Rate 1999
				White	American Indian			
Ashland, WI	16,866	16.2	15.9	87.1	10.3	15.4%	152	11.2%
Barron, WI	44,963	52.1	16.4	97.7	0.8	10.6%	385	9.1%
Bayfield, WI	15,013	10.2	16.4	88.5	9.4	13.9%	106	20.8%
Burnett, WI	15,674	19.1	20.3	93.2	4.5	11.5%	143	14.7%
Douglas, WI	43,287	33.1	14.5	95.3	1.8	13.4%	381	15.0%
Iron, WI	6,861	9.1	23.2	98.3	0.6	11.7%	69	11.6%
Polk, WI	41,319	45.1	15.1	97.6	1.1	8.9%	297	11.5%
Price, WI	15,822	12.6	18.8	98.2	0.6	10.4%	162	17.3%
Sawyer, WI	16,196	12.9	17.9	81.7	16.1	15.4%	136	16.9%
Vilas, WI	21,033	24.1	22.8	89.7	9.1	11.7%	227	19.4%
Washburn, WI	16,036	19.8	18.5	97.3	1.0	11.7%	181	16.0%
Gogebic, MI	17,370	15.8	22.6	94.2	2.2	15.7%	219	17.4%
Iron, MI	13,138	11.3	25.2	96.3	1.0	13.6%	184	3.8%
Ontonagon, MI	7,818	6.0	21.6	97.2	1.0	13.6%	98	4.1%

Sources: US Census 2000; CMS Medicare Hospice File and Denominator File 1999; Area Resource File 1999.

population of these counties is 291,396. Ten of the 14 counties have population densities below 20 persons per square mile. The service area population is older and poorer than the overall populations in the states of Wisconsin and Michigan. It is predominantly white, but also includes a significant number of American Indian people in Ashland, Bayfield, Sawyer and Vilas Counties.

### *Hospice Organization and Staffing*

RHS is governed by a 12 person board of directors. Each community currently has three representatives on the board, including the CEO of the hospital, another hospital employee (usually a member of the nursing staff), and a community representative. The board anticipates that it will transition to having two representatives from each community when Regional Hospice services begins serving a fifth community. The board meets six times a year, once in each satellite community and three times in Ashland.

At year-end 2000, the hospice had a total of 17.5 FTE staff. Three staff positions are full-time: the executive director, the RN clinical director, and the social service director. One staff member works part-time as the volunteer coordinator and part-time as a home health aide caring for hospice patients.

Two physicians share the hospice's medical director responsibilities on a part-time basis. The medical director is a family physician who is in solo practice at the tribal clinic on the Red Cliff Indian Reservation, about 26 miles from Ashland. He is board certified in hospice and palliative care, and has been working in the field of hospice care since 1987. He began working with RHS in 1996 as the associate medical director, and then switched roles with the medical director. The current associate medical director is an internist who practices in a group practice in Ashland, and has been involved with RHS since its inception. The two physicians participate in interdisciplinary team meetings, provide medical direction to the hospice teams, serve as educational resources, and take turns functioning as the primary care physician for about two patients per year who enter hospice without a primary care physician.

Each site has a team of nurses who work on a part-time, intermittent basis, caring for up to four hospice patients; their work hours vary with the site's patient caseload. They focus on dealing with pain, symptom management, and providing support for the patient and family. An RN clinical coordinator coordinates services at each site in addition to providing direct patient care.

The nurses at each site, including the clinical coordinators, share the 24 hours a day/7 days a week on call coverage for the hospice program. The hospice clinical director also shares in providing nursing coverage and taking call when the hospice is short of staff. Home health

aides are employed on a part-time basis. At year-end 2000, the hospice employed a total of 7.2 FTE RNs and 2.3 FTE aides.

Social work services are provided by the social service director at two sites, and by part-time social workers at the other two sites. The social workers help patients and families deal with end-of-life issues as well as providing practical help with health insurance problems, paperwork, and obtaining financial assistance. Each site also has a part-time chaplain, a medical liaison who is a community physician that hospice nurses can contact for medical advice, and volunteers. In 2000, a total of 58 volunteers served hospice patients at the four sites. Volunteers participate in a training course that addresses hospice program operation, pain and symptom management, grief and bereavement, roles and responsibilities of volunteers, and basic nursing skills for volunteers. Volunteers work with patients and families in patients' homes, with the bereavement followup program, and on special projects and events.

The hospice satellite sites are located 40 miles (Ironwood), 65 miles (Hayward), and 83 miles (Spoooner) away from the main office in Ashland. Consequently, RHS management and staff rely heavily on telephones for communication. The hospice management staff hold meetings via conference call with staff from each satellite site every other week to conduct case-by-case reviews of patient care and family needs.

### *Hospice Patients*

Regional Hospice Services served 193 patients in 2000. As of October 2001, the hospice census was 22 patients. The previous year's census averaged 29 patients, which was the number of patients budgeted for in 2000. The hospice has never had to turn patients away because of reaching capacity. The hospice policy is to travel no more than 50 miles one way to a patient's home, in order to be available for other patients if needed. The distance limit has not been a problem to the south and west of the hospice's service area, because other hospice providers serve these areas. However, it is more difficult to turn potential patients away because of distances in Northern Michigan, where there are no other hospice providers.

A patient receiving hospice care at home needs to have a primary caregiver in the home, but the hospice has tried to work out alternative arrangements if a patient is living alone. For example, they currently are caring for a patient who lives alone, and has 13 neighbors sharing caregiving responsibilities.

Most hospice patients have been older adults, but the hospice has also served younger patients, including two infants. The majority of patients have had cancer; in 2000, about 80 percent of the hospice patients had a cancer diagnosis. Other hospice patients have had a variety of diseases, including cardiovascular disease, chronic obstructive pulmonary disease, renal failure, ALS and Parkinson's.

The hospice has cared for American Indian patients residing on reservations near the Ashland, Hayward, and Spooner sites. A total of 15 American Indian patients were served in 2000. RHS is working with a local American Indian tribe to involve hospice staff in learning about native traditions and beliefs about death and dying.

Due to the high costs of chemotherapy and the hospice's financial constraints, the hospice has not been able to take on patients who were receiving chemotherapy in the past. As part of a move to a "mission-based approach," the hospice accepted three patients who were on chemotherapy; two of these patients later stopped the chemotherapy, but one of those was considering going back on.

In 2000, the average length of stay for the hospice at all four sites was 48.1 days; the ALOS ranged from 33.1 days in Hayward to 67.0 days in Spooner. Late referrals continue to be a concern for the hospice. The proportion of patients who spent less than 30 days in hospice care in 2000 ranged from 43 to 64 percent of patients across the four sites.

Hospice patients find out about the availability of hospice mainly through word of mouth, and referrals from physicians. Family members and friends who have had positive experiences with hospice care talk to others in the community, so they have a better understanding of how hospice care is provided. Hospice staff have also been trying to increase awareness of hospice services in the community by speaking to church groups and women's groups.

Hospice staff view management of pain and control of symptoms as the most important measures of patient satisfaction. The hospice looks at patient ratings of pain, and conducts patient and family satisfaction surveys, usually obtaining over 90% response rates.

### ***Relationship between the Hospice Program and Other Healthcare Providers in the Community***

#### Hospitals

The hospice program has strong organizational and financial ties to the hospitals in Ashland, Hayward, Ironwood and Spooner, through the hospitals' active role on the hospice board and provision of ongoing financial and in-kind support. The hospice's location in hospital-provided space in all four communities also facilitates communication between the organizations. Board members indicate that the hospice is closely associated with all four hospitals, and the hospitals get credit in the communities for sponsoring the hospice services. The Ashland hospital and hospice staff report that hospital and hospice nurses work collaboratively on pain management, and to coordinate care of hospice patients who are hospitalized.

### Physicians

Initially, the hospitals' medical staffs were one of the biggest obstacles to establishing the hospice program; some physicians were reluctant to refer patients to hospice care because of a feeling that it was "giving up on a patient." According to hospice staff, board members, and medical directors, the relationship between the hospice program and physicians has gotten better over time. A little over half of the physicians refer patients to hospice care. The referral rate varies by clinic; for example, the associate medical director's group practice refers well, while physicians in another clinic basically only refer to hospice when the patient requests it; and it depends on the physician in another clinic. Some physicians don't recognize the value of the hospice interdisciplinary model, and are still threatened by the potential loss of decisionmaking.

The hospice continues to work with physicians on pain management issues. The hospice medical directors note that their initial medical training, and that of other community physicians, included very little training on palliative care or pain control. They have found community physicians to be open to outside speakers; presenters on pain management from Duluth and the University of Wisconsin Palliative Care program were well received.

### Nursing Homes

Relationships between the hospice and area nursing homes appear to vary by facility, and among staff within the facility. In two area nursing homes that have had residents who received hospice care, the social workers were positive about the possible benefits of hospice care for nursing home patients and willing to refer patients. They report referring dying residents who need a "significant level of comfort care," and describe the benefits of hospice in terms of bringing extra nursing skills, chaplain and social work services to residents, and the ability of hospice to reach out to families. In the same facilities, however, the directors of nursing felt that dying residents' needs were being met by the nursing home's own nursing staff. One DON noted that she would refer residents to hospice if they got strong enough to go home and needed hospice care.

### Home Health

Hospice staff describe the hospice's relationships with home health agencies in the area as "not good." The private home health agencies are unwilling to refer dying patients to hospice care, and patients and families are also sometimes reluctant to switch providers. At the time of our visit, the county public health agency in Ashland was in serious financial difficulty, and the county has since closed its home care program. Bayfield County social workers refer home health patients to the hospice occasionally.

### ***Budget and Financial Issues***

RHS had operating expenses of \$1.3 million and operating revenues of \$1.24 million in 2000. Patient service revenue from Medicare (70 percent); Medicaid (16 percent), and other third-party payors and patients (14 percent) accounted for the majority of operating revenues. The hospice also received \$72,000 in direct financial support, and contributions of office space and utilities valued at \$39,800, from the hospitals in Ashland, Hayward, Spooner, and Ironwood. Additional sources of funding included special events (\$51,161) and contributions/memorials (\$114,886). In October 2001, RHS paid off the two-year loans it had received from the four hospitals to cover earlier deficits. While RHS' financial situation has improved over the past two years, the hospice's small financial margin requires that financial considerations be an important part of hospice decisionmaking, and that costs be monitored constantly.

### ***Reimbursement and Regulatory Issues***

Since Medicare patients make up the majority of patients served by RHS and most other hospice programs, Medicare reimbursement rates and regulations play an important role in determining hospice finances and policies. RHS' Medicare hospice per diem rate (about \$104 a day for routine hospice care in 2001) and certain Medicare regulations, including requirements that patients referred to hospice care have a life expectancy of six months or less, and that patients electing hospice care waive their rights to Medicare payment for any other treatment of their terminal condition, have prevented the hospice from serving some Medicare beneficiaries that could benefit from hospice services.

RHS' Medicare reimbursement has not been sufficient to allow the hospice to pay its staff at a rate comparable to other local health care settings. For example, hospice nurses are paid less than hospital nurses, making it difficult for the hospice to compete for nursing staff. Pain management costs are also a significant financial problem for RHS. The hospice's medication costs increased 86 percent from 1999 to 2000, and now account for 20 percent of all patient care expenses. Because RHS is legally a separate organization from its four sponsoring hospitals, it can not take advantage of hospital group purchasing of drugs. Instead, it obtains medications at local pharmacies, which is very expensive.

Hospices in isolated rural areas do not receive any additional reimbursement to cover the costs of travel to patients' homes, which can be considerable in terms of both mileage and staff time in large rural service areas, such as RHS'. RHS also incurs costs for hospice management and staff to travel between Ashland and the other hospice sites.

RHS medical and nursing staff are troubled by the sharp distinction between curative and palliative treatment inherent in the Medicare model of hospice reimbursement. They believe that some patients who are receiving chemotherapy could benefit from having the hospice team work with the oncologist on pain control and treatment of symptoms while the oncologist is still

“buying time” for the patient through the use of chemotherapy and other treatments. They also note that some people who are clearly dying are getting chemotherapy for palliative reasons. The issue for RHS is whether to take patients who would appropriately be getting hospice services, and spend its limited funds on very expensive chemotherapy drugs. If it does that, it may not be able to continue providing services to others who need hospice. RHS has currently been looking at this issue on a case by case basis, while it considers the financial implications of moving toward a “mission-based” philosophy of accepting all patients that could potentially benefit from hospice care regardless of cost.

The Medicare regulations allow extension of the hospice benefit beyond six months for patients who live longer than anticipated. However, the initial six month life expectancy requirement appears to have had a dampening effect on hospice referrals from some physicians in the RHS service area. In some cases, the hospice referral has been delayed until too late; a hospice nurse reported having one patient die during intake, and another on the first day of hospice care. Making a six month prognosis can be especially difficult for non-cancer diseases.

A final aspect of Medicare regulations that limits hospice use by some patients who could benefit from it is the inability to provide Medicare-reimbursed hospice services to residents whose nursing home care is being covered by the Medicare program.

### *Opportunities and Challenges to Providing Hospice Services in Rural Areas*

RHS staff describe the positive aspects of providing hospice services in rural areas in terms of their relationships with patients and their families, and the ability of the hospice program to provide pain relief and to allow patients to remain in their own homes. A current RHS patient, his family members, and a family member of a deceased hospice patient recount the benefits of hospice care in similar ways. The current patient, who had been in a great deal of pain prior to receiving hospice services, experienced considerable relief from the pain medication administered by the hospice, and was able to “get back on his feet again” and enjoy some activities away from home for a period of time. For the family member of the deceased patient, the hospice program took responsibility for the routine medical things, like getting equipment and medications, allowing the family to concentrate on the person who was dying, and to spend important time together.

Hospice staff and board members agree that travel distances, severe winter weather, and staffing are major challenges for this rural agency. The hospice has had four executive directors in its eleven year history, and has also experienced turnover in other management and staff positions. The lack of full-time positions, limited benefits, and lower salaries than other local health care positions have contributed to turnover in hospice nursing and social work staff. Financial constraints also limit staff attendance at in-service training opportunities.

For its nursing staff, RHS has tried to rely to some extent on semi-retired nurses who like the flexibility of part-time work. However, the lack of guaranteed hours and on-call coverage have been problems, and a shortage of nurses in the area is contributing to staffing difficulties. At one of the satellite sites, where it has been especially difficult to hire nursing staff, RHS hired a permanent part-time nurse to provide on-call coverage. At the time of our visit, the hospice was also considering hiring LPNs, which it had not done in the past. Since then, RHS has hired four LPNs, who are working out well as hospice staff.

### *Lessons Learned*

Based on our site visit interviews and information provided by Regional Hospice Services, we identified several important lessons about the provision of hospice care in a sparsely populated rural area, using a regional hospice model, which are summarized below.

- The use of a regional model with satellite sites can allow a hospice organization to provide hospice services over a large rural service area. However, a regional hospice located in a sparsely populated area may still have a relatively low volume of patients overall, compared with urban hospices.
- Low patient volume, travel costs, and high medication expenditures, combined with lower rural Medicare reimbursement rates, can result in financial difficulties for a rural hospice. In this case, the hospice relies on donations as well as ongoing financial support from its sponsoring hospitals to cover operating deficits.
- A freestanding hospice in a sparsely populated rural area faces multiple staffing challenges. The use of part-time, intermittent staff provides flexibility for dealing with variation in patient volume, but lower salaries, lack of benefits, and uncertainty about the number of work hours that will be available contribute to staff turnover. Travel distances and on-call coverage requirements limit the ability of a multi-site regional rural hospice to share direct care staff across sites.
- A regional hospice agency's administrative staff can supervise several sites, but it requires significant effort to build relationships and maintain ongoing communication between hospice administrative and direct care staff across sites.
- The rural communities served by RHS have multiple health care organizations (e.g., hospitals, nursing homes, and home health agencies) with varying views of how hospice care should be used, financial incentives not to refer patients for hospice care, and competing staffing needs. These factors complicate the task of coordinating care for hospice patients across agencies.

## **Hospice of North Central Florida (Gainesville, Palatka, Lake City, Chiefland and Jacksonville, FL)**

### ***Background and History of the Hospice***

Hospice of North Central Florida (HNCF) is a very large, freestanding regional model hospice that provides hospice services in a 15 county rural and urban area of north central Florida. The main office of the hospice is in the city of Gainesville (population 95,447). The hospice has three satellite sites in the rural communities of Palatka (population 10,033), Lake City (population 9,980), and Chiefland (population 1,993), and recently expanded its service area to the Jacksonville metropolitan area. The hospice satellite sites are located approximately 44 miles (Palatka), 46 miles (Lake City), and 52 miles (Chiefland) away from the main office in Gainesville.

The mission of HNCF is to serve people and their community affected by life limiting illness and loss by providing comprehensive compassionate care while respecting each person's needs, beliefs, and wishes.

HNCF started in 1978 as an all-volunteer department of the Alachua General Hospital in Gainesville, operating in Alachua County, where Gainesville is located, and in rural Bradford County. After passage of the Florida Hospice Licensure Law in 1980, HNCF became licensed and obtained a certificate of need (CON) to serve Alachua County and seven rural counties, including Bradford County. In 1985-86, HCNF became one of the first non-demonstration hospices to be Medicare certified, and four additional rural counties were added to its service area. Satellite sites were added in Palatka in 1986, Lake City in 1992, and Chiefland in 1994.

The hospice remained a department of the Alachua General Hospital until 1995-96, when the hospital was sold to Shands HealthCare, a system that includes eight not-for-profit hospitals, a network of more than 80 primary and specialty practices, and a medical staff of more than 1,000 University of Florida faculty and community physicians. HNCF's Hospice House Care Center, an 18-bed residential and inpatient facility for hospice patients without a caregiver at home or with acute needs, opened in 1997. In 2000, two rural and two urban counties were added to the HNCF service area.

The hospice is now part of Health Improvement Inc. (HII), a 501c(3) holding company that includes AvMed (Florida's largest not-for-profit health plan), The Village (a retirement center), and Alliance Medical Practice. HNCF has begun providing hospice services in the Jacksonville area, and purchased a home health agency and a durable medical equipment (DME) business. It has plans to expand all of its sites to "mixed-use facilities" that will provide home health services, DME, and inpatient residential hospice services in addition to in-home hospice services.

In addition to the hospice, the local health care system includes several hospitals and nursing homes, and many physician practices. Gainesville has four major hospitals: the 576 bed Shands at the University of Florida, the primary teaching hospital for the University of Florida College of Medicine; 367 bed Shands at AGH (formerly Alachua General Hospital); North Florida Regional Medical Center; and the Veterans Administration Hospital. There are over 450 physicians in private practice in Gainesville. Palatka has a 141 bed hospital, Putnam Community Medical Center. Lake City has two hospitals, Shands at Lake Shore with 99 beds, and Lake City Medical Center, with 75 beds. Chiefland does not have a hospital in the community; the nearest hospital is in Williston, about 26 miles away.

### ***Hospice Services and Service Area***

HNCF provides all services required by the Medicare program, including nursing and home health visits; medications, medical supplies and equipment; social work and chaplain services; hospice volunteers; and inpatient care as needed. Bereavement support is provided to family members through support groups, visits and phone calls from bereavement counselors. Hospice services are primarily provided in patients' homes; they are also provided in the Hospice Care Center, local nursing homes, and hospitals.

HNCF's large volume of patients allows it to provide more specialized services than smaller hospices. It provides radiation, chemotherapy, and dialysis when appropriate to palliate symptoms in hospice patients, and estimates that approximately 20% of patients receive one of these services. HNCF has a designated children's hospice program, Pegasus, including a camp, that helps children with life-limiting illnesses, as well as children who are dealing with the loss of a loved one.

The entire service area for the hospice includes five urban and 11 rural counties (Table 6). The total population of these counties is 1,625,078. The population density is high in the urban counties served by HNCF, but the service area also includes two rural counties that are sparsely populated: Dixie and Lafayette. In six counties, more than 20% of residents have incomes below the federal poverty line. Several counties in the service area have a significant proportion of African-American residents. The maximum distance traveled to a patient's home is about 60 miles one way from each hospice office.

### ***Hospice Organization and Staffing***

HNCF is governed by a 14 person board of directors. HII is the sole member of the hospice corporation. At the beginning, the board was responsible for fundraising. Now it balances fundraising and strategic planning responsibilities. The hospice is in the process of establishing community advisory boards for each satellite site, and each site will provide two board members to give geographic representation to the board.

**Table 6**

**Population Characteristics of Counties in Hospice of North Central Florida Service Area**

County	Population (2000)	Persons/ Square Mile (2000)	Population 65+ (2000)	Race/Ethnicity			Population < Federal Poverty Line (1997 Estimate)	Medicare Decedents 1999	Medicare Hospice Use Rate 1999
				White	Black	Hispanic			
Alachua*	217,955	249.4	9.6%	73.5%	19.3%	5.7%	18.3%	1,125	33.6
Baker	22,259	38.0	9.2%	84.0%	13.9%	1.9%	16.9%	123	25.2
Bradford	26,088	89.0	12.9%	76.3%	20.8%	2.4%	22.2%	165	36.4
Clay*	140,814	234.3	9.8%	87.4%	6.7%	4.3%	7.7%	679	28.4
Columbia	56,513	70.9	14.0%	79.7%	17.0%	2.7%	19.7%	439	31.0
Duval*	778,879	1006.3	10.5%	63.5%	27.8%	4.1%	13.4%	4,460	28.1
Dixie	13,827	19.6	17.1%	88.8%	9.0%	1.8%	23.9%	113	23.9
Gilchrist	14,437	41.4	13.6%	90.5%	7.0%	2.8%	18.4%	121	31.4
Hamilton	13,327	25.9	11.2%	58.8%	37.7%	6.4%	26.2%	60	16.7
Lafayette	7,022	12.9	12.4%	79.3%	14.4%	9.1%	24.1%	30	23.3
Levy	34,450	30.8	17.9%	85.9%	11.0%	3.9%	19.8%	307	26.7
Nassau*	57,663	88.4	12.6%	90.0%	7.7%	1.5%	9.7%	351	33.6
Putnam	70,423	97.5	18.5%	77.9%	17.0%	5.9%	22.1%	640	25.6
St. Johns*	123,135	202.2	15.9%	90.9%	6.3%	2.6%	9.4%	816	25.9
Suwannee	34,844	50.6	16.9%	84.5%	12.1%	4.9%	18.2%	330	21.8
Union	13,442	56.0	7.5%	73.6%	22.8%	3.5%	23.2%	51	45.1

\* Urban counties

Sources: US Census 2000; CMS Medicare Hospice File and Denominator File 1999; Area Resource File 1999.

In 2001, HNCF had a total of 281 full-time and part-time employees (195 FTEs). The current CEO has been with the hospice since January 2000, and has 18 years of experience in hospice care. Ten directors report to the CEO, including the medical director, clinical director, hospice and homecare operations directors, and the directors of corporate compliance and risk management, finance, human resources, development, administrative/information, and public relations/community education.

The medical director is an internist who spent 29 years in private practice in Gainesville, and has worked for the hospice for five years. As a result of his many years of practice in the area, he understands the local physician market, and has a lot of respect from community physicians. The medical director and the associate medical director are both full time positions. These two physicians, and three half-time physicians in Palatka, Chiefland and Jacksonville, provide the medical direction for all the hospice sites.

The hospice patients are primarily cared for by their own physicians, except when some symptom control is beyond the physician's skills and experience. The five hospice physicians care for about 30% of the hospice patients, including patients at the Care Center, and those who are brought into the area by their families. Responsibility for the hospice teams' medical questions and on call coverage are split among the physicians.

The clinical director is a geriatric clinical nurse specialist whose responsibilities involve certification and accreditation, and professional standards management. She directs activities related to clinical services, quality improvement, risk management, utilization review, education, pharmacy, and infection control.

HNCF has an active Quality Improvement Committee that sponsors patient, family, physician and staff satisfaction surveys. Satisfaction is measured using National Hospice and Palliative Care Organization (NHPCO) benchmarks and some questions from the Consumer Assessment of Health Plans (CAHPS). The hospice also does team level patient care audits. The Safety Committee has a medication errors and adverse reactions program, with a focus on the Care Center. The Professional Practice Committee supports teams that complete a ten percent audit to discover issues to examine. The Utilization Review Committee reviews all charts, with a separate focus on patients with greater than 180 day lengths of stay. The hospice has a data driven recertification process. A pharmacist, who is a PharmD with oncology certification, coordinates medications with physicians and reviews new medications for addition to the hospice formulary.

In the operations division, hospice staff are organized in eight teams, with a team for each site (Gainesville, Palatka, Lake City, Chiefland, and Jacksonville) and teams for hospital/nursing home care, crisis care/primary call, and the Care Center. The operations division also includes childrens' services, volunteer services, and a bereavement coordinator.

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The Gainesville, Palatka, and Care Center teams each have 25 FTE employees, Lake City has 20 FTEs, and Chiefland has 17 FTEs. Each team includes a team manager, a senior RN clinician, a senior social worker, a senior home health aide, a chaplain, nurses, social workers, home health aides/nursing assistants, a volunteer specialist, an office manager and office support staff. In addition, the Care Center team also includes housekeeping and kitchen staff.

The Central Office in Gainesville provides accounting, billing, payroll, and human resources for all sites. The Gainesville management sets policies and expects team managers to handle day-to-day issues. The team managers oversee operation of each office, deal with employee issues, staffing ratios, and team building. By design, each of the team managers has a different professional background (e.g., one is a chaplain, and another is a social worker).

The RN senior clinicians supervise the RNs, LPNs, and HHAs on their team, and provide administrative backup to the team manager. They assign RNs, do the on-call schedule, take most physician calls, review admissions, conduct monthly RN and HHA meetings, and serve on the professional practices and QI committees. Until recently, the RN Senior Clinicians also had half-time caseloads, which were eliminated because of increased administrative demands.

The hospice staffs the site teams at a ratio of one FT nurse for every 13 patients, and one FT home health aide for every 15 patients. Caseloads are assigned by town, so the number of patients per nurse may vary somewhat. At the satellite sites, nurses see an average of 3 to 5 patients per day, and usually drive about 100 to 200 miles a day.

The social workers conduct a complete psychosocial assessment of the patient and family needs within five days of each patient's admissions. They have found that a lot of families don't want to discuss end-of-life issues; often, the social worker's role is to support and to listen. The senior social workers spend half of their time with caseloads in the field and half time doing administrative work.

The chaplains see patients in the home by request and in the nursing home regularly, conduct bereavement visits, and assist with training volunteers. They will conduct funerals and memorial services, and also speak with churches and with caregivers to promote the philosophy of hospice.

The volunteer coordinator coordinates the activities of 9 volunteer specialists, who are in turn responsible for over 600 volunteers. HNCf averages about 70 volunteers per site. The volunteers provide a wide variety of activities, including respite care, cooking and serving lunch, assisting with medications using hospice procedures, reading to patients, giving time off so families can attend family events, and giving care and support to caregivers. They also run the Volunteer Attic, an upscale re-sale store, that provides funding for the hospice.

Volunteers are recruited via public relations ads in the newspaper regarding training, and from the University of Florida, junior colleges, and high schools. The hospice is listed on the county's "Volunteer Gateway" (Internet site), and also recruits via word of mouth. The Volunteer Services Department goals for 2002 include creating a youth guild of teenage and college age volunteers; recruiting volunteers to provide adjunctive therapies; enhancing the diversity of the volunteer pool; revising and standardizing the volunteer training curriculum; and enhancing the volunteer recognition program and volunteer support system.

The crisis care/primary call nurses based in Gainesville handle call coverage on weekday evenings and nights for all sites. Weekend call is covered by the sites' own nursing staff. Social workers share call for the entire agency; one social worker is on call evenings and two on weekends. This can be difficult, as the geographic area to be covered is very large.

HNCF's size allows it to offer staff benefits such as health insurance and retirement benefits. However, staffing still remains a challenge for the hospice. In particular, recruitment of social workers and RNs at the rural satellite sites is sometimes difficult. Hospice regulations require a social worker, not a counselor, on the interdisciplinary team, but the University of Florida does not have a school of social work, and the hospice does not get a lot of applications to fill social work positions. The social workers at the Chiefland site live in Gainesville and travel out to the site. Some home health aides that work out of the Lake City area also do not live there, and so are traveling long distances to work.

### *Hospice Patients*

From January 1 to December 31, 2001, HNCF served a total of 2,281 patients and their families, including 1,295 (57%) from rural counties, and 986 (43%) from urban counties. The hospice average daily census as of March 2002 was approximately 400 patients, a large increase from January 2000, when it was 238 patients. Eighty percent of the 1,946 patients admitted in 2001 were 65 and over; 17% were 45-64 years old; 2.7% were 18-44 years old; and seven patients (< 1%) were children.

The primary diagnosis for half (49.2%) of the admitted patients was cancer. Other diagnoses included circulatory (19%), respiratory (9.4%), digestive (3%), AIDS and congenital (0.8% each), and other conditions (17.8%). HNCF is seeing an increase in hospice patients with Alzheimers; determining eligibility and providing services to these patients is challenging since it is difficult to demonstrate decline in these patients, and they also can live a long time.

In 2001, the hospice's patients were 81% white, 12% African-American, 7% other, and less than one percent Latino/Hispanic and Asian. HNCF is active in community coalitions and is trying to reach out to ethnic and gay populations. The hospice is adding Spanish copies to their documentation; they are also trying to use terms that are culturally sensitive (e.g. advanced care planning, rather than terminal illness or life-threatening).

The 18-bed Care Center has two kinds of patients: long-term residential patients who are less ill and not in crisis, and patients receiving inpatient care, who usually stay less than two weeks. The Care Center is moving toward an inpatient model focused on patients with the greatest need, who are in crisis. They are handling sicker patients who need IVs, and more medications. The Care Center patients are a cross-section of the whole hospice (i.e., more female, age 60 and up, having a variety of diagnoses, including cancer, cardiac conditions, multiple sclerosis and Parkinson's disease). Approximately 80% of the patients in the Care Center come from the Gainesville area (Alachua County) and the rest from Chiefland, Lake City, and Palatka.

Care Center patients are usually long-term hospice patients who are cared for by the hospice team at home, get into crisis, and are referred to the Care Center by the team. Sometimes physicians refer directly to the Care Center. Many patients come from hospitals who discharge them to the Care Center. Sometimes patients go to hospitals as hospice patients because a bed is not available in the Care Center. The Care Center has been full almost all of the time since opening, and needs about 12 more beds now, which will require CON approval and additional fundraising.

Overall, about 80% of the hospice's referrals come directly from physicians. In making referrals, the physicians follow the Medicare local medical review policies (LMRP). However, hospice staff report that many referrals are too late, resulting in very short lengths of stay that make it difficult for patients and families to optimally benefit from hospice care.

Patients usually find out about the hospice by word of mouth, relationships with physicians and other health care providers, and hospice publicity. The hospice staff does speaking engagements to church groups, Lion's clubs, and civic organizations.

### ***Relationship between the Hospice Program and Other Healthcare Providers in the Community***

#### Hospitals

HNCF has contracts with multiple hospitals to provide inpatient services for hospice patients. The hospice management describes these relationships as very positive, noting that the hospitals give hospice patients private rooms, and that the hospice's nurse and social worker hospital liaisons work very well with hospital staff. In Lake City, both hospice and hospital staff describe their relationship as very good. Hospital staff indicate that the hospice staff respond quickly when contacted. A nurse liaison is assigned to each hospital, to ensure continuity.

### Physicians

Hospice management and staff indicate that their relationship with community physicians are positive overall, and have improved as the hospice staff have become better resources and more predictable in accepting patients. Some community physicians make a lot of hospice referrals, while others make very few referrals. In 2001, the top ten referring physicians referred just under one-fourth (24%) of the total annual hospice admissions. Physicians in outlying areas are less likely to refer patients. Some foreign physicians have cultural issues with hospice and pain medications, and gender issues are a factor for some male community physicians, who do not want to take advice from female hospice physician and nursing staff.

Among the medical issues that the hospice medical director deals with are the appropriate uses of chemotherapy and radiation for hospice patients. The hospice will pay for these services if they are aimed at palliating symptoms. If a dying patient who is receiving non-palliative radiation or chemotherapy wants to enter hospice care, the patient is told that he or she will be accepted when the non-palliative care is discontinued. The hospice physicians and pharmacist contact physicians to review inappropriate therapies.

Family physicians in two rural satellite communities described their relationships with the hospice as good, indicating that hospice staff respond well when called, provide comfort to dying patients, and try to make families an important part of the process. However, both physicians think that other physicians in their communities are not as positive about hospice as they are, because of a lack of understanding about the hospice program, and fears that the hospice may take over their patients or provide limited reimbursement.

### Pharmacies

Despite the large volume of medication used by the hospice, it would not be practical for HNCF to have its own pharmacy, because of the logistics of delivering patient medications over its extensive service area in a timely way. Therefore, the hospice contracts with over 70 local pharmacies to provide medications for hospice patients. The hospice and the AvMed Health System jointly contract with the pharmacies; both organizations benefit financially from the large volume of medications covered by the contracts.

### Nursing Homes

HNCF has contracts with several nursing homes, and has recently had an increase in the number of hospice patients in nursing homes. Relationships between the hospice and nursing homes are somewhat mixed, due to a variety of issues related to reimbursement and contracting, frequent leadership changes at some nursing homes, and a range of attitudes toward hospice among local nursing home administrators and staff.

Administrators at two nursing homes in rural communities served by HNCF were generally supportive of hospice care, and positive about their relationship with HNCF. One administrator, who usually has about 4 or 5 hospice patients in her facility, said that someone from the hospice was at the nursing home every day - the hospice nurse came every two days, the medical director frequently, and the chaplain and social worker provided family support. She described the hospice staff as knowledgeable, and indicated that the nursing home staff had attended training at the hospice central office, as well as having in-service training from the hospice nurse at the nursing home. The other administrator, whose facility has had a recent increase in hospice patients, had 11 hospice patients at the time of our visit. She noted that the nursing home's hospice patients are sicker in general and require more care.

Both administrators felt that there was a need to educate residents' families about hospice. They also expressed several concerns about reimbursement, including Medicaid rates being much lower than Medicare skilled nursing rates, the burden on families of paying private pay room and board rates for non-Medicaid eligible patients receiving Medicare hospice benefits, and the lag in payment resulting from the fact that the hospice does not pay the nursing homes until it gets paid.

#### Home Health Agencies

HNCF does not interact much with home health agencies. The hospice management believes that nursing homes have more patients who should be referred to hospice than home health agencies do. Hospice staff acknowledge that while home health agencies sometimes want to keep patients who would be hospice appropriate, patients also are often reluctant to switch nurses. In these cases, the hospice tries to arrange a transition time for the patient to say goodbye to their nurse and adjust to the hospice nurse.

#### ***Budget and Financial Issues***

HNCF had operating revenues of approximately \$20.5 million in 2001. Patient service revenues came from Medicare (84 percent); Medicaid (8-9 percent), and other third-party payors (3-4 percent). Until about two or three years ago, the hospice was subsidized, first by the hospital where it started, and then by the AvMed Health System. Now, it is financially independent and has a positive operating margin. The hospice receives about \$1.25 million annually from fundraising; these funds are used to enhance care and fund unfunded programs, including Pegasus (the childrens' hospice program); Transitions (the pre-hospice program); and Healing Hearts (the grief support program which provides services to hospice families and communities).

The CEO describes HNCF as "an HMO for dying patients," explaining that the hospice bases its operations on sound business principles, looks for efficiencies, and counts on a large patient volume to be financially viable. It avoids unnecessary care, but unlike many hospices, it

does not fear taking on expensive patients, or have restrictive admissions criteria. Instead, HNCF tries to objectively determine the appropriateness of therapies such as chemotherapy, radiation, and dialysis for the individual patient, and relies on volume to balance the costs of expensive patients with less expensive ones.

The Care Center was funded through community donations of \$4.5 million, and philanthropy covers part of the cost of operating the Center. Currently, the payor mix at the Care Center is approximately 65% Medicare, 20% Medicaid, and 15% private insurance. For patients receiving inpatient care, the Care Center receives the Medicare inpatient rate of about \$500/day. For residential patients, the hospice requests patient fees since costs are about \$200/day, and the Care Center only receives the routine home care rate of about \$100/day.

### ***Reimbursement and Regulatory Issues***

The State of Florida allows a 12 month life expectancy for hospice care, and HNCF thinks that the life expectancy criterion in federal Medicare regulations should also be 12 months. HNCF has found that it is not cheaper to provide care in rural areas than in Gainesville, but Medicare pays the hospice less for rural patients because of the hospice wage index. HNCF supports direct reimbursement from CMS for physician assistants and nurse practitioners caring for hospice patients. In addition, HNCF believes that hospices should receive outlier payments for high cost patients, as more and more expensive medications and treatments are palliative in nature. A final area of regulatory concern is that the Medicare fiscal intermediary for north central Florida interprets the Medicare LMRP guidelines so they seem to be regulations, from the hospice's perspective.

### ***Opportunities and Challenges to Providing Hospice Services in Rural Areas***

HNCF's size allows it to achieve economies of scale, provide more resources, a broader range of services, and more financial stability than would be likely be available in Chiefland, Lake City, and Palatka, if those rural communities had small independent hospices. At the same time, HNCF still faces challenges serving its rural sites, including travel distances and logistics, staffing, limited resources in rural communities, and the need to keep a strong sense of local ownership in each rural community. The recent rapid growth in patient volume and staffing has brought additional challenges, because more people are involved in decisionmaking, and communication takes longer.

Hospice management in Gainesville and management as well as staff in Chiefland and Lake City all cite the distances traveled to patients' homes as a major challenge to serving rural areas. They indicate that staff spend a lot of indirect time traveling, which results in less direct care time; the long distances complicate on-call coverage; and staff safety is sometimes a concern in isolated areas. The distances make it especially difficult for staff (e.g., chaplains and medical directors) who cover several counties. Travel distances also lead to some equity

concerns for rural staff regarding hospice policies; for example, having the same caseload standard of 13 patients per nurse and flat rate payments to staff for on-call visits in rural areas, although the distances traveled are greater than in Gainesville.

Because of its size, HNCF is able to provide resources to facilitate staff recruitment and retention such as personnel support, better benefits than smaller hospices could likely offer, promotional opportunities for experienced employees within the hospice, and central office weekday evening and night on-call coverage for the rural sites. However, staffing at the rural sites, particularly of social worker positions, remains a challenge, and is complicated by varying caseloads. Poverty and lack of family and/or community resources also make it difficult to serve some hospice patients, such as those who do not have heat or washers and dryers in their homes.

To keep a strong sense of local ownership in each rural community, donations given to each hospice site are kept locally, and the hospice literature is separate for each site. HNCF recently changed the names of the Chiefland, Lake City and Palatka sites to reflect their communities; the Chiefland site is now Hospice of the Tri-Counties, the Lake City site is Hospice of the Suwannee Valley; and the Palatka site is Hospice of the Lakes. This change is viewed positively by team managers at the rural sites, who indicate that they like having a feeling of independence and autonomy.

### ***Lessons Learned***

The Hospice of North Central Florida case study gave us a unique opportunity to examine how a large, urban-based regional hospice model provides care from three rural sites. The lessons learned from this case study are summarized below.

- A regional hospice model that serves rural areas can achieve a large patient volume by having an urban population base, and obtaining a relatively high proportion of hospice-eligible patients in a very large geographic service area.
- The large regional model has numerous advantages for the hospice's rural sites, including the ability to provide a broad range of services for patients, financial stability, economies of scale in purchasing of pharmaceuticals and supplies, administrative and personnel resources and expertise, shared call coverage and backup staffing.
- With a large regional hospice, it is very important to have local staff who develop long-term relationships with community physicians and other health care providers, and to pay special attention to each site's local identity to maintain local financial support and volunteers.
- The Hospice Care Center provides a setting for long term hospice patients who are in crisis, or have medical needs that can not be met at home, to receive hospice care in a homelike

setting. Philanthropic support was critical to establishment of the Center and remains essential to ongoing operation of the Center.

- Florida's Certificate of Need law contributes to the success of the large regional model by limiting competition from other hospices in HNCF's service area. The state also has a long history of leadership in the hospice field.

## CONCLUSIONS

The hospices described in this study were purposefully selected to represent different models of providing hospice care in rural settings. As such, they are a rich source of information about how hospices with different organizational characteristics, and at various stages of development, operate in diverse rural communities and health care systems. The case studies also illustrate the importance of several issues that have been raised in previous studies of hospice care, and demonstrate the impact of public policies regarding hospice care on hospices serving rural areas. Consequently, many of the lessons learned from the case studies have implications for hospices in other rural settings and for public policy regarding the provision of hospice care, which are described below.

- **Rural hospices face additional financial challenges beyond those arising from trends affecting the entire hospice industry, such as shorter lengths of stay and increasing medication expenses. Travel costs are an important financial issue for many rural hospices.**

Several recent studies, including a Milliman USA actuarial analysis of hospice costs and revenues, a Medicare Payment Advisory Commission (MedPAC) study of hospices, and an analysis of Medicare regulations affecting end-of-life care, suggested that many hospices, especially small rural hospices, are likely to have costs that are not adequately covered by the current Medicare payment system (MedPAC, 2002; Cheung et. al., 2001; Huskamp et. al., 2001).

For rural as well as urban hospices, Medicare is the payer for the vast majority of hospice patients. Medicare hospice per diem rates are generally lower for rural hospices than urban hospices, because the rates are adjusted using a hospice wage index. However, the per diem rates are not adjusted for other differences in costs that may be significantly higher for rural hospices. For example, travel to patients' homes, including mileage and staff time, is likely to be much more costly for rural hospices.

Small hospices, which are much more common in rural areas, have fewer patients over which to spread fixed costs, and are especially vulnerable to financial problems arising from high cost "outlier" cases, since the Medicare per diem reimbursement system is based on average costs for a hospice caseload. These hospices are limited in their ability to take on high cost

patients who could benefit from expensive palliative radiation or chemotherapy as well as traditional hospice care. Small hospices also are less likely to benefit from economies of scale in purchasing pharmaceuticals and medical supplies.

Like many urban hospices, rural hospices rely on fundraising, donations, and subsidies from local hospitals or sponsoring agencies to survive financially and to provide specialized programs.

The financial challenges facing rural hospices were clear for the case study hospices. All four hospices rely on fundraising and donations to help cover their costs. Only one of the four hospices, the very large, urban-based regional model, currently has a positive financial margin. (Prior to its recent large growth in patient volume, this hospice was experiencing revenue shortfalls, and receiving financial support from a sponsoring hospital system.) The three smaller rural-based hospices are currently receiving financial subsidies from sponsoring hospitals in two cases, and the county in one case. The smaller hospices are also limited in their ability to provide high cost treatments such as expensive palliative radiation or chemotherapy, because they do not have a large enough volume of patients over which to average these costs under the per diem payment system.

- **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, 7 days a week.**

Hospice care, like other health care services, is labor intensive. The task of recruiting and retaining hospice staff is complicated by the need to staff for fluctuations in patient census, to provide coverage 24 hours a day, 7 days a week, and to find staff who are willing to care for dying patients, primarily in the patients' homes, on an ongoing basis. For rural hospices, staffing challenges are exacerbated by shortages of nurses, medical social workers, and other types of health professionals in many rural areas.

The hospices profiled in this study employ a variety of strategies to address their staffing needs, including:

- ★ sharing staff with a parent home health agency or hospital; for example, having nurses who care for both hospice and home health patients, or a chaplain who ministers to both hospital and hospice 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 help prevent staff burnout by providing variety in patient caseloads and spreading responsibility for on-call coverage over a larger number of staff;
- ★ having staff perform multiple roles; for example, having volunteer coordinator responsibilities as part of a social work, nursing, or home health aide position;

- ★ employing hospice staff as hospital employees, with the same salaries and benefits;
  - ★ having hospice staff live in the community where a hospice is headquartered and travel to a satellite site to provide care;
  - ★ hiring a medical director, nurses, and social workers who want to work part-time in hospice; for example, individuals who are semi-retired, or want to balance their work time with family needs;
  - ★ hiring staff to provide on-call coverage on nights and/or weekends; and
  - ★ providing on-call coverage to satellite sites from a central location.
- **Concern about late referrals to hospice care and the need to improve pain management for dying patients are common themes across different types of rural hospice models.**

Nationally, the average length of stay in hospice has declined significantly since 1992. In 2000, the median length of stay was 25 days, and one-third of hospice patients died in 7 days or less (NHPCO, 2002). Analysis of survival times for Medicare hospice patients has demonstrated that the majority of patients, especially cancer patients, are enrolled in hospice relatively late in the course of their terminal illness (Christakis and Escarce, 1996; Virnig et. al., 2002). Late referrals raise concerns about the ability of hospices to provide patients with optimal pain and symptom management, and help them come to closure on end-of-life issues. Very short lengths of stay also have a negative impact on hospices' financial status.

A variety of reasons are likely responsible for late referrals to hospice and non-use of hospice services by many decedents who could have benefitted from hospice services, including physicians' problems accurately predicting the length of time a terminally ill patient may live, physicians' desires to have the patient maintain a hopeful attitude, physician and hospice concerns about having patients live beyond the 6 month prognosis defined in Medicare regulations, and reluctance on the part of physicians, patients, and family members to stop aggressive treatment (GAO, 2000; Daugherty and Steensema, 2002; Friedman, Harwood, and Shields, 2002).

Early outreach programs for patients who are terminally ill, but have a life expectancy of more than six months, can help smooth the transition from aggressive care to palliative care and help address problems with late referrals to hospice care (Friedman et. al., 2002). One of our case study sites, Hospice of North Central Florida, has established Transitions, a pre-hospice program, to address this need; the hospice uses fundraising dollars to support this program. NHPCO has suggested that the Medicare program consider reimbursing hospices for palliative care consultations provided to patients at the time of diagnosis with a life-

threatening illness (Miller et. al., 2002). These early consultations could include counsel on palliative care planning, pain and symptom management, and social and emotional issues, for patients who do not meet the 6-month life expectancy criteria for hospice but could benefit from palliative care expertise and resources.

Among interviewees at the case study sites, there was general agreement that community physicians' attitudes toward hospice are a key factor influencing the number and timing of hospice referrals in rural areas. Within a rural community, physicians' attitudes towards hospice care may range from strongly supportive to quite negative. Similar to urban physicians, the majority of rural physicians are usually willing to make some referrals to hospice, particularly if it is requested by the patient and family. Rural hospices face additional challenges working with physicians in areas where there are physician shortages, a lot of physician turnover, or a significant portion of patients obtain medical care outside the local community.

Although many rural patients find out about hospice care through relatives, friends and neighbors, lack of awareness about hospice care, and patient and family perceptions of hospice care as "giving up," are also factors influencing late referrals in the communities we visited. Hospices agree that there is still a large need for community education about hospice care in many rural areas.

Improvement of pain management for dying patients is a goal for all hospices. Many community physicians who are currently practicing in rural as well as urban areas had little training in palliative care and pain control in their initial medical education, and concerns about potential overuse or abuse of narcotics sometimes inhibit effective pain control for dying patients. Cultural and gender issues can also complicate communication between hospice staff and community physicians regarding pain management.

The Robert Wood Johnson Foundation has funded a number of national initiatives to improve end-of-life care, including professional education programs for practicing physicians and nurses. The Education for Physicians in End-of-Life Care (EPEC) program, which was initiated by the American Medical Association in 1998 and is now located at Northwestern University Medical School, uses a train-the-trainer model to educate physicians on the essential clinical competencies required to provide end-of-life care, including pain management and symptom control. The EPEC program has experienced considerable demand for its training sessions and materials, and has trained approximately 600 physicians and other health-care professionals (Weisfeld et. al., 2000; EPEC, 2002).

In the rural communities we visited, effective strategies used to increase awareness of hospice care include community-wide fund-raising events, public presentations to civic and religious organizations, and publication of hospice-related stories in local newspapers. Rural hospices are trying to encourage more timely referrals for hospice care through frequent staff

contacts with community physicians, and distribution of written information materials about hospice at local clinics and hospitals. They are working on improved pain management through regular communication from medical directors to community physicians, and sponsorship of continuing education opportunities on hospice and pain control. Hospice medical directors and nursing staff are also providing pain control expertise through in-services and pain consultations in some rural hospital and nursing home settings.

- **The smaller size and limited number of health care organizations in rural communities make the task of coordinating care for hospice patients across health care settings somewhat easier in rural areas than in many urban areas. However, coordination between hospices and hospitals, nursing homes, and home health agencies in rural communities on end-of-life issues is still complicated by organizational “turf” issues and Medicare and Medicaid reimbursement policies.**

Nationally, hospitals and hospice programs have begun to partner in collaborative approaches to the provision of palliative care, but face significant challenges in financing, regulation, and institutional culture (NHPCO and Center to Advance Palliative Care in Hospitals and Health Systems, 2001). These collaborative initiatives include offering professional education about hospice care, developing specialized hospice inpatient units, facilitating the admission of hospital patients onto the Medicare hospice benefit, and developing new, non-hospice-benefit palliative care services.

The proportion of nursing home residents using the Medicare hospice benefit differs significantly within and across states, which has raised questions about access to the hospice benefit for nursing home residents (Miller and Mor, 2002). Several issues complicate nursing home and hospice relationships, including federal and state concerns about the financial arrangements between hospices and nursing homes with regard to dually eligible Medicare-Medicaid beneficiaries, different treatment orientations (rehabilitative versus palliative care) and differences in Medicare conditions of participation for hospices and nursing homes (Gage et.al., 2000).

The task of coordinating care for hospice patients across health care settings should be somewhat easier in rural areas than in many urban areas. Rural communities’ smaller size and limited number of health care organizations may facilitate the development of working relationships between hospice staff and other health care agencies’ staff. However, depending on the organizational structure of the hospice and the local health care market, rural hospices may also compete with nursing homes, home health agencies, and hospitals in their service area for patients and staff.

In the rural communities we visited, rural hospices generally had positive relationships with local hospitals. A number of the rural hospitals have a specially designated and furnished 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 served by the hospice appears to facilitate cooperative relationships with hospital staff, as well as promote continuity of care for hospice patients in those facilities.

The rural hospices' relationships with nursing homes and home health agencies are more complex. In some cases, hospice nurse liaisons facilitate cooperative relationships with nursing homes. In other cases, however, nursing homes appear reluctant to refer patients for hospice care. Factors contributing to this reluctance included the perception among some nursing home staff that hospice does not add much to their own care of dying patients, as well as reimbursement issues, including the significantly lower rates paid for nursing home patients by Medicaid compared to Medicare skilled nursing rates and lags in payment resulting from hospices not paying nursing homes until the hospice is paid by Medicare.

- **Residential options are needed in rural areas for hospice patients without a caregiver at home, or who are too ill to be cared for by an elderly spouse. However, these programs require considerable financial support from a community.**

Although residential hospice options are needed, the costs of residential care are not adequately covered by reimbursement. Medicare does not cover room and board costs, leaving patients to pay out-of-pocket, or rely on Medicaid if they are eligible. Two of the case study hospices are successfully providing residential hospice care, with significant financial support from their communities. Clearly, residential hospice care centers in rural areas are meeting a need, but require community financial support, both to become established and to maintain operations.

- **The appropriate hospice model for a specific rural area depends on a variety of factors, including the size, density, and demographic characteristics of the population in the service area, the configuration of the local health care system, relationships between local providers, and how other health care services are being provided in the area.**

Hospital-based hospices are the most common organizational model in rural areas, accounting for 35% of rural hospices. Freestanding hospices and home health agency- based hospices are also common in rural areas, accounting for 34% and 31% of rural hospices, respectively. A critical issue with all of these organizational models is whether the hospice can obtain a sufficient volume of patients to be financially viable, or alternatively, achieve economies of scale through sharing of fixed costs, joint management and staffing, and purchasing of medical supplies and pharmaceuticals in cooperation with the hospice's parent agency.

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, e.g., having local staff who develop relationships with community physicians and other health care providers, and 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 may benefit from long term relationships with community members who have obtained other health care services from the hospice's parent organization. These models can facilitate continuity of care for patients who move from the hospital or home health care 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.

The decision about what type of model should be used to provide hospice services in a rural community should consider current health care utilization and referral patterns, for example, where community residents are usually hospitalized or referred for speciality care. Organizational experience and expertise in hospice and related types of care is important. Community trust in the organization selected to provide the service and agreement among health care providers about the decision are key factors.

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 results of these case studies indicate that hospices in rural settings, while sharing common goals with those serving urban areas, face special challenges that have limited access to hospice services for rural residents. The challenges faced by hospices in rural settings should be considered in designing and implementing state and national initiatives to improve end-of-life care through changes in health professional education and health care financing, especially the Medicare program.

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