

Rural Hospice in the United States:
An Annotated Review of the Literature

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INTRODUCTION

The Medicare Payment Advisory Commission (MedPAC) noted in 2011, that 1.2 million Medicare beneficiaries received hospice services from more than 3,500 providers. Medicare expenditures that year totaled about \$13.8 billion (MedPAC, 2013). Utilization rates reported by the National Hospice and Palliative Care Organization (NHPCO), and the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS) illustrated a consistent incline in the number of hospice patients served over the last seven years (NHPCO, 2013). The NHPCO has estimated that in the most recent year (2012), 1.6 million patients received hospice services. Of the 1.65 million patients reported in 2011, an estimated 64% died under hospice care, nearly 19% remained on the hospice census (known as carryovers), and nearly 17% were discharged. Additionally, dividing the number of patients that had died under hospice care by the total number of U.S. deaths, the NHPCO estimated 44.6% of all U.S. deaths were under the care of a hospice team in 2011 (NHPCO, 2012).

As the supply of hospice increased by 53% between 2000 and 2010, so did Medicare expenditures. However, hospice services comprised only two percent of the total Medicare expenditures in 2008 – the least of any direct patient service provider under the program (CMS, 2013c). The 2012 MedPAC report also noted that hospice margins averaged only 2.8% in 2011 (2012).

While research has begun to explore the characteristics and use of hospice in the United States, studies and national hospice agencies have not begun to identify issues and characteristics specific to rural hospice services. Literature with a rural focus is relatively dated with some of the more recent and reputable research using data from 2004 or earlier (e.g., Mosovice, Virnig, & Durham, 2005). Those studies that have specifically addressed rural hospice care have either

limited the scope of the study by reviewing data files related to particular diagnoses, or one level of hospice care (i.e., only home-based care, or only hospice care in an inpatient setting) (e.g., Kyusuk, & Burke, 2012; Lackan, Ostir, Freeman, Mahnken, & Goodwin, 2004; Temkin-Greener, Zheng, & Mukamel, 2012). Though the previous research does not offer a comprehensive understanding of rural hospice care, the literature does illustrate later hospice enrollment among rural residents, and higher use rates among urban populations (e.g., Keating, Herrinton, Zaslavsky, Liu, & Ayanian, 2006; Lackan, Ostir, Freeman, Mahnken, & Goodwin, 2004; McCarthy, Burns, Davis, & Phillips, 2003).

Following is an annotated review of hospice literature; specifically, resources that have addressed rural hospice care, access, and utilization. The presentation of information begins with an overview of hospice organizations and agencies cited most frequently in the literature along with a discussion of their most recent research. The organizations and agencies that published the most relevant hospice information included: (a) the National Hospice and Palliative Care Organization (NHPCO); (b) the National Association for Home Care & Hospice (NAHC); and (c) the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS). An annotated review of other research follows comprised of sources deemed most appropriate in answering the questions around rural hospice services. The review is organized by date of publication, not necessarily organized by date of the data source or research.

METHODS

The search for reputable and current research began by asking two questions:

1. What is known about rural hospice care (e.g., access, utilization, quality)?
2. What differences, if any, are there between rural and urban hospice use, utilization, and/or care?

The search was employed through four avenues of exploration: (a) the search of electronic databases, to include those available to students and faculty at the University of North Dakota; (b) review of all articles identified on the *Resources* pages of national hospice organizations, associations, and centers (to include the Centers for Medicaid and Medicare Services); (c) articles provided by staff at the Rural Assistance Center (RAC) housed within the University of North Dakota School of Medicine and Health Sciences Center for Rural Health; and, (d) a search through reference lists of relevant studies and published (peer reviewed) literature reviews.

Abstracts of each study were reviewed to determine if they addressed hospice care independent of home care and palliative services. It was apparent that a significant body of research did not differentiate between the three services, instead discussing all end-of-life care services collectively. If the study explored various forms of end-of-life care and provided a separate discussion of hospice services, as defined by CMS, it was included. Table 1 presents the description of hospice, palliative, and home care, services.

Table 1. Description of Hospice, Palliative, and Home Health Care Services

Description of Services	
Hospice	<ul style="list-style-type: none"> • Patients are enrolled through a referral from the primary care physician and a hospice care provider. • The hospice program is overseen by a team of hospice professionals, and is administered in the home. • Hospice often relies upon the family caregiver, as well as a visiting hospice nurse. • A patient must generally be considered to be terminal or within six months of death to be eligible for most hospice programs or to receive hospice benefits from your insurance. • Most programs concentrate on comfort rather than aggressive disease abatement. By electing to forego extensive life-prolonging treatment, hospice patients can concentrate on getting the most out of the time they have left.
Palliative Care	<ul style="list-style-type: none"> • Palliative care is a method of administering “comfort” care and increasingly, is offered most prevalently by hospitals. • Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often at the facility where a patient will first receive treatment. These individuals will administer or oversee most of the ongoing comfort-care patients receive. • While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility, or nursing home that is associated with a palliative care team. • There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not. • Since there are no time limits on when you can receive palliative care, it acts to fill the gap for patients who want and need comfort at any stage of any disease, whether terminal or chronic. In a palliative care program, there is no expectation that life-prolonging therapies will be avoided.
Home Health Care & Home Care	<ul style="list-style-type: none"> • Home Health Care and Home Care are both a form of home and community-based services (HCBS). • A range of personal, support, and health services are provided to individuals in their homes or communities to help them stay at home and live as independently as possible. • Most people who receive long-term care at home generally require additional help either from family or friends to supplement services from paid providers. The collection of these resources are needed to provide personal care such as help with activities of daily living (e.g., bathing and dressing); assistance with managing medications; or supervision. • There is no requirement participants forgo curative treatment, or be in the last months of life. • <i>Home Health Care</i>: Home health care typically includes skilled, short-term services such as nursing, physical, or other therapies ordered by a physician for a specific condition. • <i>Home Care</i>: Home care services are most often limited to personal care services such as bathing and dressing, and often also include homemaker services such as help with meal preparation or household chores.

Source: National Care Givers Library, 2013.

The search was limited to articles published between 2000 and 2013. However, those with more recent information were given priority in the annotated review to follow. For example, research from MedPAC has led to several reports to congress; only the most recent is

discussed here. Articles were also excluded from discussion if the studies were conducted outside of the United States, though the reference lists of these articles were included in the search for additional resources.

Many hospice resources focused on a single diagnosis, primarily that of cancer or malignancies (e.g., Cristakis, & Escarce, 1996; MedPAC, 2000; Virnig, McBean, Kind, & Dholakia, 2002). Studies that explored a limited set of diagnoses were not included in the annotated review, though their reference lists were evaluated for additional articles. The search concluded when the reference lists for each publication had reached saturation – when those resources listed had already been referenced by other sources, and had been evaluated.

NATIONAL ORGANIZATIONS

National Hospice and Palliative Care Organization (NHPCO)

The NHPCO is the largest nonprofit membership organization for hospice and palliative care programs and professionals in the United States (NHPCO, 2013a). Beyond advocating for quality end-of-life care, the NHPCO also provides education, monitors Congressional and regulatory activities, and provides an annual review of hospice growth, delivery, and quality of care (NHPCO, 2012; 2013a). Data for their annual report are derived from the NHPCO membership database records, as well as voluntary submission by hospice organizations to a Data Analysis Reporting Tool (DART) housed within the organization. The NHPCO also produces the *Journal of Pain and Symptom Management*.

The NHPCO provides six tools for data submission among its members: (1) Patient Outcome Measures (POM); (2) Family Evaluation of Hospice Care (FEHC); (3) Family Evaluation of Palliative Care (FEPC); (4) Family Evaluation of Bereavement Services (FEBS); (5) Survey of Team Attitudes and Relationships (STAR); and (6) the National Data Set (NDS) (NHPCO, 2012). Table 2 offers a brief description of each tool and how the data are both submitted and shared.

Table 2. NHPCO Performance Measure Surveys/Reports

Performance Measures	NHPCO Description	Data Submission and Reports
Patient Outcome Measures (POM)	POMs include patient-centered measures related to managing pain within 48 hours of admission (Comfortable Dying/NQF #0209), avoiding unwanted hospitalizations/avoiding unwanted CPR, and patient safety.	<ul style="list-style-type: none"> • Hospice programs submit data quarterly into DART* • Reports available to NHPCO members the 1st of June, September, December, and March
Family Evaluation of Hospice Care (FEHC)	The FEHC is a post-death survey designed to yield actionable information that reflects the quality of hospice care delivery from the perspective of family caregivers. Hospices that submit FEHC data to NHPCO receive quarterly reports that include individual hospice results plus state and national results for comparison.	<ul style="list-style-type: none"> • Hospice programs submit data quarterly into DART* • Reports available to NHPCA members the 1st of May, August, November, and February

Performance Measures	NHPCO Description	Data Submission and Reports
Family Evaluation of Palliative Care (FEPC)	The FEPC is a post-death survey that captures family members' perceptions about the quality of the palliative care that their loved ones received – whether that care was provided by a hospital-based consult service or by a hospice program offering palliative care. The questions on the FEPC survey are based on those in the FEHC survey, with wording modifications appropriate to palliative care service delivery.	<ul style="list-style-type: none"> • Hospice programs submit data bi-annually into DART* • Reports available to NHPCA members August 15, and February 15
Family Evaluation of Bereavement Services (FEBS)	The FEBS survey is designed to evaluate bereavement services from the perspective of the recipients of the services. The survey takes a comprehensive approach by including questions on a wide range of services, with instructions to respondents to skip those questions that do not pertain to their experience with bereavement services.	<ul style="list-style-type: none"> • Hospice programs submit data bi-annually into DART* • Reports available to NHPCA members August 1, and February 1
Survey of Team Attitudes and Relationships (STAR)	STAR is the first staff job satisfaction survey designed specifically for the hospice field. STAR was developed by researchers at the University of Pennsylvania in collaboration with NHPCO and is a benefit of membership for NHPCO provider members.	<ul style="list-style-type: none"> • Hospice programs have staff complete an electronic survey after their roster has been updated in the NHPCO member database • Programs may access their reports online anytime • National report available for purchase from NHPCO
National Data Set (NDS)	<p>NDS summary results provide useful information to hospices for defining strategic goals, setting operational targets, and improving care delivery. The National Data Set represents a comprehensive compilation of information on hospice operations, including:</p> <ul style="list-style-type: none"> • Who provides care • Who receives care • The range, cost, and quality of hospice services 	<ul style="list-style-type: none"> • Hospices that are not current members of NHPCO can also submit data through DART* • While there is no fee to participate, membership is required to access summary reports

*DART: The Data Analysis Reporting Tools (DART) was created at Brown University by The Center for Gerontology and Healthcare Research. The system serves as the location for hospice programs to submit data for the FEHC, NDS, FEPC, POM, FEBS, and Quality Partners Self-Assessment System.

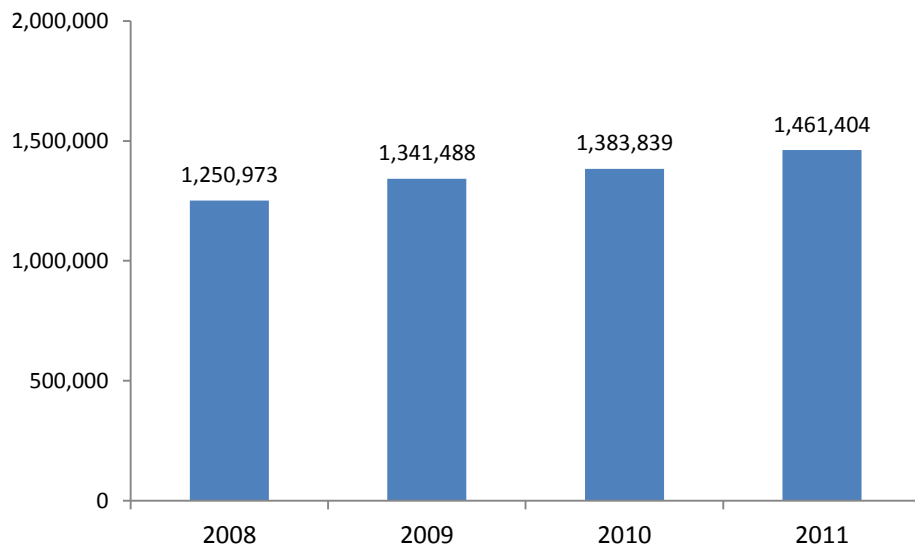
Source: NHPCO, 2012.

The NDS includes program, patient, process, and financial statistics and is considered a comprehensive compilation of hospice trends in the U.S. Data from the NDS are reported in both an abridged, publically available, review of *Facts and Figures: Hospice Care in America* and a complete report (*National Summary of Hospice Care*) intended solely for active hospice and palliative care providers who are NHPCO members.

NDS data is voluntarily self-reported by active hospice providers and includes hospice organizations that are not members of the NHPCO. To validate their national estimates, the NHPCO performed a comparative analysis with data from the National Center for Health Statistics' (NCHS) National Home and Hospice Care Survey (NHHCS). The NDS data fell within the 95% confidence interval of the NHHCS's 2007 results (NHPCO, 2012). Although the NHPCO's data are derived from a convenience sample, the estimates have been found reliable and accurate. Data are reported at the national level and hospice care variables are stratified by agency type, patient level of care, and/or payer mix; future research should also include a rurality variable. The NHPCO data are used to answer the following four questions related to hospice care: (1) who provides hospice care?; (2) who are the patients cared for by hospice? (3) how much and what kind of services do hospice patients and their families receive?; (4) how much money does hospice cost (NHPCO, 2013c)?

Based on their member database and NDS, the NHPCO estimated that in the most recent year (2012), nearly 1.6 million patients received hospice services (NHPCO, 2013a). Of the roughly 1.5 million hospice patients in 2011, 64% died under hospice care, nearly 19% remained on the hospice census (known as carryovers), and nearly 17% were discharged (NHPCO, 2012). While the total number of hospice patients served has been on a gradual incline (see Figure 1), the NHPCO reported nearly identical variation of rates between the above categories of care at year-end for both 2010 and 2011 (NHPCO, 2011; 2012). Additionally, using their estimate of patients that had died under hospice care and dividing that by the total number of U.S. deaths, the NHPCO stated 44.6% of all deaths were under the care of a hospice team in 2011 (NHPCO, 2012). While this figure has not been determined for 2012, NHPCO did identify that approximately 1,113,000 deaths in the U.S. occurred while under hospice care in 2012.

Figure 1. NHPCO: Total Hospice Patients Served by Year (Estimate)



Source: NHPCO, 2011; 2012; 2013.

The NHPCO estimated roughly 5,500 active hospice programs in 2012 to include both primary locations and satellite offices. Roughly 63% of these hospice organizations hold a for-profit status in 2012 (NHPCO, 2013a). The number of for-profit hospices has been steadily increasing over the last decade while the percent of not-for profit organizations has been on a gradual decline (NHPCO, 2013a).

A hospice agency may be a free-standing/independent hospice, part of a hospital system, part of a home health agency, or part of a nursing home. It was reported that in 2012, 57.4% of all agencies were free-standing or independent hospices (NHPCO, 2013a). While the percentage of agencies identified as free-standing/independent, part of a hospital system, or part of a home health agency had either experienced a slight decline or remained largely unchanged among three agency types, Table 3 identifies a significant increase in the percent of agencies that were part of a nursing home between 2010 and 2011 (NHPCO, 2011; 2012; 2013).

Table 3. NHPCO: Agency Type by Year

Agency Type	2009	2010	2011	2012
Free Standing/Independent Hospice	57.5%	58%	57.5%	57.4%
Part of a Hospital System	21.4%	21.3%	20.3%	20.5%
Part of a Home Health Agency	19.5%	19.2%	16.8%	16.9%
Part of a Nursing Home	1.4%	1.4%	5.2%	5.2%

Source: NHPCO, 2011; 2012; 2013.

Outside of agency type, the NHPCO identified hospice patients' locations at death. Primary place of residence was the location of care at death for 66% of hospice patients in 2012 (NHPCO, 2013a). Place of residence was defined as a patient's private residence (41.5%), nursing home (17.2%), or residential facility (7.3%). Place of residence at death was followed by hospice inpatient facility and acute care hospital respectively. See Table 4.

Table 4. NHPCO: Location of Hospice Patients at Death by Year

LOCATION OF DEATH	2009	2010	2011	2012
Patient's Place of Residence	68.6%	66.7%	66.4%	66%
Private Residence	40.1%	41.4%	41.6%	41.5%
Nursing Home	18.9%	18%	18.3%	17.2%
Residential Facility	9.6%	7.3%	6.6%	7.3%
Hospice Inpatient Facility	21.2%	21.9%	26.1%	27.4%
Acute Care Hospital	10.1%	11.4%	7.4%	6.6%

Source: NHPCO, 2011; 2012.

While 2011 estimates presented a significant increase in the number of hospice agencies associated with a nursing home with 2012 estimates unchanged (Table 3), the percent of hospice patients dying in a nursing home remained largely unchanged (Table 4). The NHPCO offers no explanation.

Hospice agencies range in their staff clinical knowledge/experience and size. Agency size may be categorized using total admissions over a 12 month period or daily census. In 2012, 77.4% of hospice agencies had fewer than 500 total admissions per year. The average daily census across all agency types was 148.5 patients. The median daily census provides a more

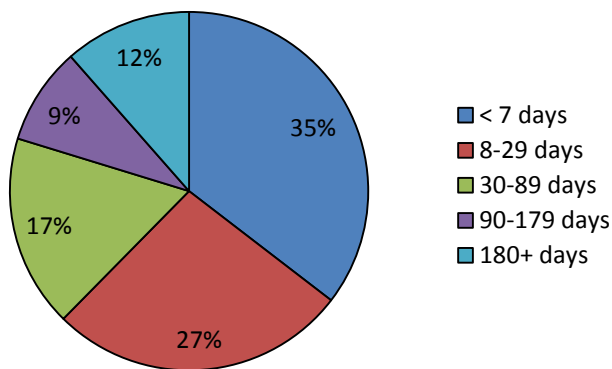
accurate estimate of agency size because the average is skewed by national corporate hospices that may serve more than 1,500 patients a year. The median average daily census in 2012 was 92 patients, up from 71 in 2011(NHPCO, 2012; 2013).

The NHPCO report identifies the percentage of hospice agencies by type and overall hospice agency volume. However, the report does not describe agency size by type. While there is an increase in the number of agencies that were part of a nursing home, there was no discussion of the number of patients (agency size) that this agency type served that year.

The length-of-stay (or length of service) refers to the total number of days that a hospice patient received hospice care (regardless of agency type, or location). Length-of-stay (LOS) is best understood by the median rate; averaging the LOS is often a poor estimate as it is influenced by extreme values. In 2012, the median LOS was 18.7 days (down from 19.1 in 2011), while the average was 71.8 days (up from 69.1 in 2011) (NHPCO, 2013a).

Figure 2 illustrates that a majority of hospice patients (nearly 63%) died or were discharged within 29 days of admission in 2012; unchanged from 2011 (NHPCO, 2013a). Longitudinal data from the NHPCO had previously reported a trend toward shorter lengths of stay (NHPCO, 2011; 2012; 2013).

Figure 2. NHPCO: Proportion of Patients by LOS in 2012



Source: NHPCO, 2013, Figure 5, p. 5.

In 2012, more than half of hospice patients (56.4%) were female and 84.5% of all hospice patients were over the age of 65 (NHPCO, 2013a). Additionally, White/Caucasian Americans disproportionately received hospice care compared to all other race categories accounting for 81.5% of the hospice patient population (NHPCO, 2013a). Finally, Medicare was identified as the primary payer group for hospice agencies, accounting for roughly 84% of patients receiving hospice care and 89% of patient care days.

Research conducted by the NHPCO informs many hospice providers and stakeholders. Additionally, the NHPCO annual review reports current information related to hospice patient and provider characteristics, locations and level of care, and the roles of paid and volunteer staff; however, there is no stratification of rurality.

Through the NHPCO, members have access to a variety of educational opportunities and resources. One resource developed through the combined efforts of the NHPCO, the Center to Advance Palliative Care, and the National Rural Health Association is the *Providing Hospice and Palliative Care in Rural and Frontier Areas: A Rural Toolkit* (2005). The toolkit stated that 39% of America's hospices self-identified as rural, and 40% of programs served individuals that resided in both rural and urban locations (National Rural Health Association (NRHA), 2005). While the toolkit shared relevant information related to enhancing care and improving access, the data discussed are now out-of-date and may be unreliable as a result of individual self-reporting.

National Association for Home Care & Hospice (NAHC)

The NAHC is a nonprofit organization representing the nation's home care and hospice facilities. While providers of home care and hospice are the primary members of the association, other members include corporate entities, associate members, state association members, and allied members. The NAHC's mission is to encourage the development and delivery of high

quality medical, social, and supportive services to the aged, infirm, and disabled (NAHC, 2013a).

Unlike the NHPCO, the NAHC does not have a specific instrument for data collection, nor do they publish an annual report. However, NAHC's research department provides information to its members and the public regarding the latest data available for home care and hospice. The focus of the research team at NAHC is to "improve the delivery of quality care, understand the political environment, and ensure the future of the home care and hospice industry" (NAHC, 2013b).

For NAHC members, the research department produces state fact sheets regarding the number of agencies, patients served, number of visits, and annual Medicare reimbursements. In addition, the state fact sheet information includes ownership type, number of full-time equivalent staff, and average OASIS scores (OASIS is a home health units outcome and assessment information set). These reports may also be purchased by non-members. The most recent report provided data analysis, but did not include a discussion of the results.

A review of current research conducted by the NAHC staff resulted in few studies focused solely on hospice care. Additionally, neither their current research, nor their state fact sheets specifically address rural end-of-life services.

Hospice Association of America (HHA)

The Hospice Association of America (HAA) is a national organization, under the NAHC, responsible for lobbying for hospice, and advocating on behalf of the industry before Congress, regulatory agencies, other organizations, the courts, and the public (HAA, 2010; NAHC, 2013e). The most recent report published by the HHA regarding hospice care was in November 2010.

The report provided a discussion around hospice care through data received from CMS, the NHPCO, and the NAHC among others (HAA, 2010).

While the report presented a review of existing data sources highlighting the number of hospice patients, certified hospices, and financial expenditures, there was no discussion of patient demographics (beyond race), or geographical trends in hospice services (beyond state rates). Additionally, there was no discussion of the data beyond presentation and much of the data were out of date. The most recent data source was from 2009 with other data files reporting their most recent rates from 2005 (HAA, 2010).

**Centers for Disease Control and Prevention (CDC), National Center for Health
Statistics (NCHS)**

The National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC), provides statistical information that guides actions and policies to improve the health of the American people (CDC, 2013). Key activities of the NCHS include fielding surveys and analyzing data, such as the National Home and Hospice Care Survey (NHHCS). This survey was first conducted by the NCHS in 1992 and focuses on end-of-life care. It is part of a series of home health and hospice agency surveys, and has been conducted in 1993, 1994, 1996, 1998, 2000, and 2007 (CDC, 2010; 2007). The data provide descriptive information on home health and hospice agencies, their staffs, services, and patients.

Survey responses for 2007 were collected through in-person interviews with agency directors and their staffs. All 1,036 respondents were either certified by Medicare and/or Medicaid, or were licensed by a state to provide home health and/or hospice services. Additionally they were either currently, or had recently, served home health or hospice patients (CDC, 2013). The NCHS does not produce a comprehensive report on the study's findings, but

instead produces a series of articles and fact sheets using the data (CDC, 2007). Results from the 2007 NHHCS are presented in several sources discussed throughout the annotated review that follows.

ANNOTATED REVIEW OF RURAL HOSPICE RESEARCH

Medicare Payment Advisory Commission (MedPAC). (2012). *Report to Congress: Medicare Payment Policy, (Chapter eleven: Hospice services)*. Washington, D.C.: MedPAC. 281-308.

The Medicare Payment Advisory Commission (MedPAC) is an independent Congressional agency established to advise the U.S. Congress on issues impacting the Medicare system. Chapter eleven of the MedPAC report provided a recommendation to Congress regarding payment rates of hospice care. The report utilized data from a variety of CMS files to include: the Medicare Beneficiary Database; 100% hospice claims standard analytic file; Medicare hospice cost reports; Provider of Service file; fiscal year spending from CMS Office of the Actuary; and many others. Data were from 2002-2010.

The report stated that in 2010, hospice use increased across all demographic and beneficiary groups. While the authors noted that there were still unexplained disparities in hospice utilization across racial and ethnic groups, they did not say the same of hospice utilization among urban and rural beneficiaries. Instead, MedPAC wrote that use rates for beneficiaries in the five geographic¹ regions increased between “1.7 percentage points and 3.0 percentage points compared with the prior year, continuing the substantial upward trend in hospice use that has occurred across these areas over the past 10 years” (p. 289). There was no mention in the report if this overall growth exacerbated, maintained, or alleviated the disparity in care between rural and urban communities.

¹ The five regions classified in the report include: (1) urban; (2) micropolitan; (3) rural, adjacent to urban; (4) rural, nonadjacent to urban; and (5) frontier.

Table 5 illustrated that the average annual percentage point change was lowest among frontier and rural, nonadjacent to urban communities. Hospice utilization had increased across all beneficiary locations; however, the percentage growth had been more significant for: urban; micropolitan; and rural, adjacent to urban residents. Additionally, the report did not mention where these beneficiaries had received hospice care. It may be that the increase in utilization among rural adjacent to urban beneficiaries reflected increased use of hospice services that were provided in an urban community. Discussion does not address utilization of a hospice by the organizations' locations. Meaning, an increase in utilization of hospice services among rural, adjacent to urban residents may be the result of increased utilization of urban services.

Table 5. Percent of Medicare Descendants who used Hospice by Beneficiary Location

	2000	2007	2008	2009	2012	Averaged Annual Percentage Point Change 2000-2009	Percentage Point Change 2009-2010
Urban	24.3	40.4	41.7	43.5	45.4	2.1	1.9
Micropolitan	18.5	34.5	35.8	37.5	39.8	2.1	2.3
Rural, adjacent to urban	17.6	33.6	34.7	36.9	38.7	2.1	1.8
Rural, nonadjacent to urban	15.8	30.0	30.5	32.8	34.5	1.9	1.7
Frontier	13.2	26.0	25.7	27.1	30.1	1.5	3.0

Source: MedPAC, 2012, Table 11-2, p. 288.

MedPAC stated that the number of providers had also increased by 53% in last 10 years, with increases in both rural and urban areas. However, while the number of hospice providers increased by 62% in urban communities between 2000 and 2009, the number of rural hospice providers increased by only 31%. Rural areas experienced a decline of 1% in the most recent year (2009-2010) while urban hospices increased access by an additional 5%.

Again, the report did not address the results as an indicator of disproportionate hospice care between urban and rural communities, but instead, indicated that the increase among

providers in urban locations may actually have been providing services to rural and frontier beneficiaries. While this may have been the case, it overlooks the issue of access among rural and frontier residents, assuming that increased services in urban locations are meeting the needs of those individuals.

The MedPAC report also addressed average and median lengths of stay (LOS), as well as rates of live discharge. However, these data were not presented using geographic stratifications. The other variables discussed within the lens of rural and urban hospice care related to Medicare payments and providers’ costs. MedPAC reviewed margins through the 2009 cost-reporting year, as well as variations in costs per day. Rural hospices were found to have lower costs per day (\$127) than their urban counterparts (\$145) in 2009. In this analysis, MedPAC did not identify all five geographic regions, but instead, compared only rural and urban providers. It is unknown if micropolitan or frontier were classified under “rural” for this review.

With regard to hospice margins, MedPAC examined hospice margins by “degree of rurality based on the type of county (i.e. urban, micropolitan, rural adjacent, rural nonadjacent based on the urban influence codes) in which the largest share of its patients lived” (p. 303). See Table 6 for the rural and urban hospice margins from 2003 through 2009.

Table 6. Rural and Urban Hospice Medicare Margins, 2003-2009

	Percentage of Hospices 2009	2003	2004	2005	2006	2007	2008	2009
Urban	70	7.4	5.9	5.1	7.1	6.3	5.6	7.6
Rural	30	0.1	-2.3	0.2	0.8	1.4	1.3	3.1

Source: MedPAC, 2012, Table 11-10, p. 302.

MedPAC reviewed the 2009 data further and found that while hospices serving rural areas aggregately (as presented in Table 6) had lower margins than those serving urban residents, margins did not decrease as the degree of rurality increased (see Table 7). Hospices serving

frontier beneficiaries actually reported higher Medicare margins than those hospices serving urban residents.

Table 7. Medicare Margins by Type of County Served, 2009

Hospice Provider by Predominant Type of County Served	Aggregate Medicare Margin	Percent of Hospices
Urban	8.0%	70%
Rural	3.7	30
Micropolitan	3.1	18
Rural, adjacent to urban	3.5	6
Rural, nonadjacent to urban	6.5	6
Frontier*	8.8	4

Note: Excludes above-cap hospices. Predominant county served is determined using the beneficiary’s address registered with Social Security and reflects the type of county that accounts for the largest share of the provider’s caseload. Frontier is defined as a county with a population density of 6 people per square mile or less.

*Providers with more than 10% of patients residing in frontier counties.

Source: MedPAC, 2012, Table 11-12, p. 304.

The MedPAC report to Congress provided data regarding the variation in access, utilization, and Medicare margins between rural and urban hospices. However, the discussion did not address disproportionate care; instead, the MedPAC focused on the growth of access and utilization across geographies.

Chung, K., & Burke, S. C. (2012). Characteristics of hospice patients utilizing hospice inpatient/residential facilities. *American Journal of Hospice and Palliative Medicine*.

Chung and Burke used data from the 2007 National Home and Hospice Care Survey (NHHCS) to develop a baseline regarding utilization of hospice inpatient/residential facilities (HIRFs). Data were further reviewed to identify patient characteristics (to include location of utilized agency) associated with patient enrollment in a HIRF. A national representative sample of 2.7 million (84%) of all discharged hospice and home health patients were included in the initial review, regardless of their discharge status (death or live discharge). Final results were

based on 4,727 patients discharged from hospice in 2007 – deemed representative of the estimated 1.03 million patients discharged from hospice that year.

Researchers used both place at admission and place at discharge to create the measure HIRF utilization. If a patient had utilized a HIRF at either their admission to hospice care, or at discharge (death or live discharge), they were counted. However, the study could not account for patients who may have transferred into and out of a HIRF during his or her care. This lack of patient follow-up may be a significant gap because regardless of hospice location of enrolment or discharge, 17% of all hospice patients changed their location of care at least once during their hospice stay.

Chung and Burke reported that, in 2007, 7% of hospice patients were placed in a HIRF upon admission, while 14% of hospice patients were discharged from a HIRF. Overall, roughly 14% of hospice patients utilized a HIRF during all, or part, of their hospice stay compared to 13% of patients who received care in a hospital. Five patient characteristics were positively associated with HIRF use: (1) receiving care in a hospital before hospice enrollment; (2) having a different location upon admission and discharge; (3) being discharged within less than one week; (4) death discharge; and (5) being enrolled in a hospice agency located in a metropolitan area.

Characteristics associated with hospital hospice use were similar to those accessing a HIRF; however, patients whose hospice agencies were located in a rural area were more likely to receive care in a hospital during their hospice stay. The study also reports that only 4% of hospice agencies were located in rural areas.

Finally, the report stated that roughly 90% of patients in HIRFs at discharge were receiving a general inpatient (GIP) respite level of care in 2007 (the highest reimbursement rate

per day a hospice agency may receive); the remaining 10% were receiving the routine level of care. GIP care is generally reserved for hospital services; however, only 77% of hospice patients that received care in a hospital were receiving GIP level reimbursement in 2007.

The authors recommend that future research should explore utilization and growth of HIRFs, especially in rural areas where both access and utilization are low. They suggest HIRFs could absorb the disproportionate number of rural hospice patients that access hospice care provided in a hospital setting. However, the discussion also noted that the Office of the Inspector General (OIG) denied over 40% of the 770 reviewed GIP claims in 2008, and has since employed stricter rules of reimbursement.

The reinforcement of the hospice reimbursement scale has, and continues, to reduce claims payments to HIRFs, increasing reimbursement rates for routine level of care while decreasing the number of claims for GIP care (Ball, 2010; OIG, 2012). This trend in reimbursement has led to the decline of HIRFs, making study of their value and utilization less important nationally. In addition, prior to this study, the Centers for Medicare and Medicaid Services (CMS) began a rural hospice demonstration project where the Secretary of the United States Department of Health and Human Services concluded that the HIRF model was not effective and should not be applied to other rural hospices (Sebelius, 2011).

While the authors identified rural residents as disproportionately accessing hospice services in a hospital setting in 2007, the variable *rural* was conceptualized as “neither metropolitan nor micropolitan” with no further definition of rurality. Additionally, this study discussed characteristics of patients that had accessed care in a HIRF compared to a hospital setting. Data illustrated a majority of patients began hospice care in the home or other residential facility (83%), not a hospital. No argument was made for why hospice patients that had utilized

HIRFs were then compared only to those that had accessed care in a hospital setting and not to those who had received care in other hospice locations.

Temkin-Greener, H., Zheng, N., & Mukamel, D. B. (2012). Rural-urban differences in end-of-life nursing home care: Facility and environmental factors. *The Gerontologist*, 52(3), 335-344.

This study examined rural-urban differences in the quality of end-of-life (EOL) care provided to nursing home residents. Nursing homes were categorized as either urban, large town, small town, or isolated rural. See Table 8 for this study’s definition of each.

Table 8. Study Definitions of Urban/Rural

Location	Study Definition
Urban	City with a population > 50,000 and its commuting area
Large Town	Population of 10,000-49,999 and its commuting area
Small Town	Population of 2,500-9,999 and its commuting area
Isolated Rural	Fewer than 2,500 residents, primarily commuting to a tract outside an urban area or cluster

Source: Temkin Greener, Zheng, & Mukamel, 2012.

Quality of care was conceptualized through three risk-adjusted measures of end-of-life quality, to include: (1) use of a hospice (considered characteristic of better quality EOL care); (2) in-hospital death (associated with lower quality EOL care); and (3) presence of severe pain.

Using individual, facility, and county data from CY2005-2007 obtained from eight national data sources, the analytical sample consisted of 915,688 decedent long-term residents (aged 65 or older) from 13,206 facilities. The eight data sources included the: (a) 100% Medicare denominator files; (b) Minimum Data Set (MDS); (c) Medicare Standard Analytical Files for inpatient and hospice claims; (d) the Area Resource File for 2007; (e) the Provider of Service file for third quarter of 2007; (f) the ZIP code level Rural-Urban Commuting Area Codes; and (g) the Brown University’s Long-Term Care Facts website.

“Analysis of facility-level characteristics indicated statistically significant ($p < .001$) differences between urban-rural nursing homes with regard to each of the three unadjusted

outcomes” (p. 339). Additionally, the authors found that prevalence of hospice use among nursing home residents in 2007 decreased by rural/urban status from 37.15% in urban areas to 24.32%, 21.71%, and 19.08% in large town, small town, and isolated rural areas, respectively. With regard to access, nursing homes located in counties with a greater number of hospice providers had better hospice quality measures and better pain quality measures. While this was noted as a significant finding, it was not addressed in the discussion of rural-urban classification. However, earlier in the report, the researchers identified a statistically significant difference in the number of hospice providers in urban (9.60) and isolated rural (.50) communities.

In the discussion, the authors stated that among the three quality measures, pain was the only variable to show no change with regard to locality. Review of hospice enrollment and in-hospital death each suggested better quality EOL care in urban nursing homes, with the lowest quality scores among isolated rural communities. In measuring in-hospital death, the data suggested that rural nursing homes were more likely to hospitalize residents prior to death than their urban counterparts. Increased in-hospital deaths in rural communities were believed to have been related to the availability of hospice care.

While this study only reviewed quality of EOL care among nursing home patients, it did reiterate what other literature had found – that access and utilization of hospice care was lower in rural communities than in urban, and residents of rural nursing homes were receiving poorer EOL quality of care with regard to in-hospital deaths. Study findings may not be generalizable to current hospice utilization as the data utilized for review date back to 2007; hospice services and access have grown significantly since that time. The study did not address type of hospice service, nor if the rate of in-hospital deaths controlled for hospice patients receiving respite care

in a hospital setting at that time of study. Finally, the study did not control for the availability of various hospice services in each community.

Carlson, M., Barry, C., Schlesinger, M., McCorkle, R., Morrison, S., Cherlin, E., Herrin, J., Thompson, J., Twaddle, M., & Bradley, E. (2011). Quality of palliative care at US hospices: Results of a national survey. *Medical Care, 49(9), 803-809.*

In 2004, the four leading hospice and palliative care organizations in the United States came together to develop clinical practice guidelines for quality palliative care, known as the National Consensus Project (NCP). Two years later, “the National Quality Forum (NQF) adapted the guidelines into a set of preferred practices for palliative and hospice care quality” (p. 803). This study was the first to review the adoption of the NQF preferred practices among hospice providers and is also one of the only articles, to date, to review quality reporting compliance among hospice providers.

The research team surveyed 706 eligible hospices, after beginning with a national random sample of 914 hospices operating in the United States between September 2008 and November 2009. The sample was drawn from the Medicare Provider of Services file. The survey was sent electronically to the identified sample, and had a completion rate of 84%. Respondents were asked to respond to six questions regarding the characteristics of their hospice facility², and to identify which of the ten patient-centered preferred practices and seven family-centered preferred practices had been implemented. See Table 10 for the list of practices.

Between September 2008 and November 2009, 10% of hospices reported implementing all 17 practices. Hospices were more likely to be meeting measures related to family-centered care (26% had met all seven measures) than patient-centered care (21% had met all ten

² Hospice facility characteristics included: (1) size (no. of patients per day); (2) years providing hospice care; (3) hospice is a member of a chain; (4) hospice is vertically integrated; (5) ownership; (6) census region (New England, Middle Atlantic, East North Central, West North Central, South Atlantic, East South Central, Mountain, Pacific).

measures). The least common preferred practices among hospices were: (a) including family preferences for care in the discussions of patients’ plans of care at initial admissions, routinely, and when clinical conditions change; and (b) including patient goals of care in discussion of patients’ plans of care.

Hospice characteristics that had the greatest impact on the number of implemented preferred practices were hospice size and hospice chain membership (Table 9). While classification of the nine census regions identified geographic disparity, they did not identify variation in quality measure adoption between urban and rural hospices. Rather, the authors addressed rural disparities within the context of their finding that the size of the hospice, and chain membership were positively correlated with increased compliance in preferred practices. Authors noted these associations were apparent in both bivariate and adjusted analyses.

Table 9. Preferred Practices by Hospice Size and Chain Membership

	Total	Hospice Size (No. of Patients Per Day)				Hospice is a Member of a Chain	
		> 20	20-49	50-99	≥ 100	Yes	No
Patient-centered preferred practices							
Hospice provides 24-hour crisis management phone access to patients and families	97%	95%	97%	98%	99%	99%	97%
Nurses, social workers, physicians, and pastoral care/chaplains are expected to attend interdisciplinary team meetings	94%	90%	95%	95%	97%	95%	94%
Hospice tracks data on patient satisfaction at least annually	94%	90%	95%	95%	95%	98%	93%
Hospice tracks data on patient falls/serious injuries and medication errors at least annually	90%	84%	88%	93%	94%*	98%	88%*
Hospice staff monitors pain at least every few days	87%	82%	88%	90%	87%	92%	86%
Hospice has a physician on-call both evenings and weekends	82%	73%	81%	82%	95%*	91%	81%*
Advance directives, identity of legal surrogate, and patient preferences for place of death are included in discussions of patients’ plans of care at least at initial admission	82%	77%	81%	84%	85%	89%	80%*
Hospice staff monitors symptoms at least every few days	71%	70%	73%	72%	71%	72%	71%
Hospice regularly uses a standardized assessment tool for pain and symptom management	66%	59%	62%	70%	74%*	72%	65%
Patient goals of care are included in discussions of patients’ plans of care at initial admission,	55%	54%	49%	59%	60%	71%	53%*

	Total	Hospice Size (No. of Patients Per Day)				Hospice is a Member of a Chain	
		> 20	20-49	50-99	≥ 100	Yes	No
when clinical conditions change, and on a routine schedule							
Family-centered preferred practices							
Hospice tracks data on family caregiver satisfaction with hospice overall at least annually	97%	92%	97%	99%	99%*	91%	89%
Hospice tracks data on family caregiver satisfaction with bereavement services at least annually	89%	81%	91%	93%	93%*	100%	96%*
Hospice screens family caregivers who may be at increased risk for complicated grief and major clinical depression before the patient’s death	89%	87%	90%	86%	86%	92%	89%
Hospice provides bereavement services to family caregivers beyond 12 mo after the patient’s death if the family desires it	88%	82%	89%	88%	88%*	93%	88%
Hospice has an ethics committee or ombudsmen to address conflicts of interest	79%	70%	73%	87%	87%*	87%	77%*
Bereavement staff provide predeath planning	78%	70%	79%	77%	77%*	86%	76%*
Family preferences for care are included in discussions of patients’ plans of care at initial admission, when clinical conditions change and on a routine schedule	45%	40%	40%	50%	50%	60%	42%*

*P < 0.05 for overall w2 test

Source: Carlson, Barry, et al., 2011, Table 3, p. 806.

This study identified that hospices were concerned with quality of care, and willing to adopt preferred practices. However, implementation of the 17 practices was self-reported by the hospice facilities which may have overestimated the actual level of compliance. The study did not specifically identify the facilities’ rural/urban status; the authors discussed variation in adoption among small rural hospices within the lens of chain membership and hospice size.

Carlson, M., Bradley, E., Qingling, D., Morrison, R. S. (2010). Geographic access to hospice in the United States. *Journal of Palliative Medicine*, 13(11), 1331-1338.

Through review of the 2008 Medicare Provider of Services file, and the 2000 U.S. Census data the authors provided a comprehensive estimate of geographic access to hospice care. Access to care was conceptualized as living within 30 minutes and within 60 minutes driving time to a hospice provider. Estimated driving time was measured from the center of each Census tract to the nearest hospice. The authors recognized this may have led to under or over

estimating the time from each individual’s residence to a hospice provider, but noted this is the preferred method of estimating the distance to various health care providers among other research.

In 2008, approximately 88% of the U.S. population lived in a community within 30 minutes driving time to at least one hospice, with 98% of residents within 60 minutes. An estimated 74% of the U.S. population lived in communities within 30 minutes of at least two hospices, and 94% lived within 60 minutes of two or more hospices. The mean and median number of minutes between community centers and hospice providers were 15 and 9 minutes respectively, but the range of access was between 0 and 403 minutes.

Factors significantly associated with being within 30 minutes driving time to a hospice included: (a) higher population per square mile; (b) a lower percentage of the population who were age 65 or older; (c) higher median household income; and (d) lower percentage of the population with a less than high school education. When reviewing the variable population per square mile, independent of other characteristics, the average driving time to a hospice provider was significantly greater among the most rural communities (identified as quartile one in this research). See Table 10.

Table 10. Time to the Nearest Hospice by Community Population

Population per square mile	Average Minutes to Nearest Hospice	Standard Deviation (SD)
Quartile 1: Less than 250*	33.1	25.1
Quartile 2: 250-2099	13.9	14.4
Quartile 3: 2100-5499	8.6	9.5
Quartile 4: ≥ 5500	6.5	4.6

* p < 0.001 for comparison of group means using Welch’s analysis of variance.

Source: Carlson, Bradley, Qingling, & Morrison, 2010, excerpt from Table 1, p. 1333.

In their presentation of state-level variation, the research team identified eleven states that had “10% or less of their population in communities further than 30 minutes driving time of a

hospice” (p. 1333). Eight states were noted as having more than 30% of their residents living further than 30 minutes driving time, to include North Dakota and South Dakota. These two states were also classified as having had more than 10% of their population further than 60 minutes driving time from a hospice.

Unlike with state variation, the authors did not discuss the percentage of communities within 30 and 60 minutes of a hospice by rurality (quartile). Instead, the findings noted that in 2008, approximately 35 million individuals lived more than 30 minutes from a hospice and 6 million people were living in communities greater than 60 minutes from a hospice. The study concluded that there continued to be evidence of “greater geographic access to hospice in more urban compared to more rural areas” (p. 1335).

The distance estimates did not address provided services. While an organization that holds a hospice license may be within 30 or 60 minutes of driving from a given location, there is no evidence that the identified hospice provides services to that community. Many hospices do not provide hospice services outside of a designated distance/area.

Campbell, C., Merwin, E., & Yan, G. (2009). Factors that influence the presence of a hospice in a rural community. *Journal of Nursing Scholarship*, 41(4), 420-428.

While other studies have explored rural and urban variations of hospice care, access, and utilization, Campbell, Merwin, and Yan sought to identify socioeconomic, physician-related, and rural-urban factors that may have influenced the presence of a certified hospice in 2005. Data were analyzed from the Area Resource File (2005) from the Department of Health and Human Services. The research team explored factors influencing the presence of a hospice in 3,140 counties in the United States.

The three categories of rurality (metro, nonmetro adjacent to metro, and nonmetro nonadjacent to metro) were conceptualized using the nine rural-urban areas in the Department of Agriculture's classification. The 2000 Census was employed to determine population data.

Among the 3,140 counties in 2005, the mean physician rate was 12.61 and the mean number of Medicare hospices was .83. The study did not discuss the median number or range of either variable, which may have been more appropriate given the likely outliers. The average physician rate in metropolitan counties (18.99) was much higher than that of nonmetro adjacent (8.98) and rural (9.48) counties. The percentage of counties with at least one certified hospice was also much higher in metro areas (59%) than nonmetro adjacent (39%) and rural (36%) counties. However, it was important to note that while there was geographic variation in county access to a Medicare certified hospice, a majority of counties did not have a hospice provider.

The authors argue that it may not have been rurality that affected the presence of a hospice, but the rate of physicians in the given county. The study found that the "odds of a county having at least one Medicare-certified hospice increased 10% for every 1-unit increase in the county physician rate" (p. 425). This trend was true across counties within a given geographic region as well – meaning, even among all metro counties, every additional physician increased the likelihood of a hospice in that community. The physician county rate was the only variable found to significantly influence the presence of a Medicare-certified hospice in all three rural-urban areas.

This study explored how rurality, race-ethnicity, and physician access influenced the presence of a hospice in U.S. counties for the year 2005; however, the research team did not study the interaction of the identified variables or how that may influence access to hospice in

rural counties. Additionally, their Census data are now nearly 13 years old, with the demographic data dating back nearly eight years.

Madigan, E., Wiencek, C., & Vander Schrier, A. (2009). Patterns of community-based end-of-life care in rural areas of the United States. *Policy, Politics & Nursing Practice*, 10(1), 71-81.

This study was limited in scope and not necessarily generalizable to the United States rural population, but it addressed the variation in access between community-based end-of-life care options. Researchers explored rural access to skilled nursing facilities, home health agencies, and hospices among persons 65 years of age or older in eight states³.

Names and addresses of home health agencies and skilled nursing facilities (certified and active between July 2005 and June 2006) were obtained from the Medicare website. A list of hospices was obtained from the National Hospice and Palliative Care Organization's (NHPCO) membership database. A hospice does not have to be Medicare-certified to be a member of the NHPCO; however, the authors did note that in 2002, 90% of hospice patients received care from NHPCO members. Additionally, the list from the NHPCO was cross-checked (with a mean agreement of 92%) with an additional list of hospices taken from www.healthcarehiring.com.

Data from the 2000 Census were employed to determine rural classification. The Urban Influence Codes from the U.S. Department of Agriculture's Economic Research Service were condensed into three categories: (a) metropolitan counties; (b) micropolitan counties; and (c) rural counties. ZIP codes of home health agencies, skilled nursing facilities, and hospices were matched with the UIC categories and classified as either metro, micro, or rural.

Research found that a significant proportion of rural counties did not have hospice availability in 2005-2006. For all eight states, other than Vermont, more than 60% of the rural counties had no hospice provider. The author's recognized that this finding only addressed the

³ (1) Arkansas; (2) California; (3) Louisiana; (4) Montana; (5) New York; (6) Ohio; (7) Texas; and (8) Vermont.

presence of a hospice in a given rural community and did not consider access to a hospice in an adjacent county. However, research has not shown that adjacent access increases hospice utilization among rural residents. Additionally, hospices in adjacent counties may not provide services to all surrounding communities as a result of distance and constrained Medicare payments.

Table 11 illustrates that in rural communities (within the eight identified states) the greatest disparity in community-based end-of-life care was with regard to hospice services. Fewer counties had no skilled nursing facility, followed by no home health agency. While findings could be substantiated by including data from across the U.S., this report illustrated inadequate access to hospice care in rural areas.

Table 11. Percentage of Rural Counties with no Community-Based End-of-Life Providers by Type of Provider in 2006

	Total Number of Rural Counties (Total Counties)	Percentage of Rural Counties with no HHA	Percentage of Rural Counties with no SNF	Percentage of Rural Counties with no Hospice
Arkansas	37 (75)	13.5	5.4	91.9
California	13 (58)	76.9	38.5	61.5
Louisiana	17 (64)	41.2	23.5	88.2
Montana	46 (56)	65.2	21.7	69.6
New York	11 (62)	18.2	9.1	72.7
Ohio	19 (88)	47.4	0	73.7
Texas	133 (254)	58.6	27.8	90.2
Vermont	5 (14)	20	0	0

Note: HHA = home health agency; SNF = skilled nursing facility

Source: Madigan, Wiecek, & Vander Schrier, 2009, Table 3, p. 78.

Connor, S., Elwert, F., Spence, C., & Christakis, N. (2007). Geographic variation in hospice use in the United States in 2002. *Journal of Pain and Symptom Management*, 34(3), 277-285.

Geographic variation in hospice use was determined by measuring the hospice utilization ratio among persons 65 years of age or older who died in 2002. Data were derived from: (a) the Standard Analytic File – Hospice, maintained by CMS; (b) the National Center for Health Statistics’ Compressed Mortality Files; and (c) the complete CDC death certificate records. The

authors identified that the numerator and denominator used to determine the hospice utilization ratio came from different sources, adding that “both data sources are beneficiary-encrypted public-use databases [requiring] certain statistical assumptions” to be made (p. 278).

The author’s reviewed hospice utilization rates with regard to patient’s cause of death, geographic region, state, sex, race, and age. It was estimated that roughly 28.6% of older Americans utilized hospice in 2002. Female and white descendants were more likely to have used hospice care than their counterparts; however, the authors did not note if these differences were statistically significant. Additionally, hospice utilization rates were positively correlated with age. Hospice utilization also varied by cause of death with higher utilization among those dying of malignancies (65%), kidney disease and nephritis (55%), and Alzheimer’s disease (41%)⁴.

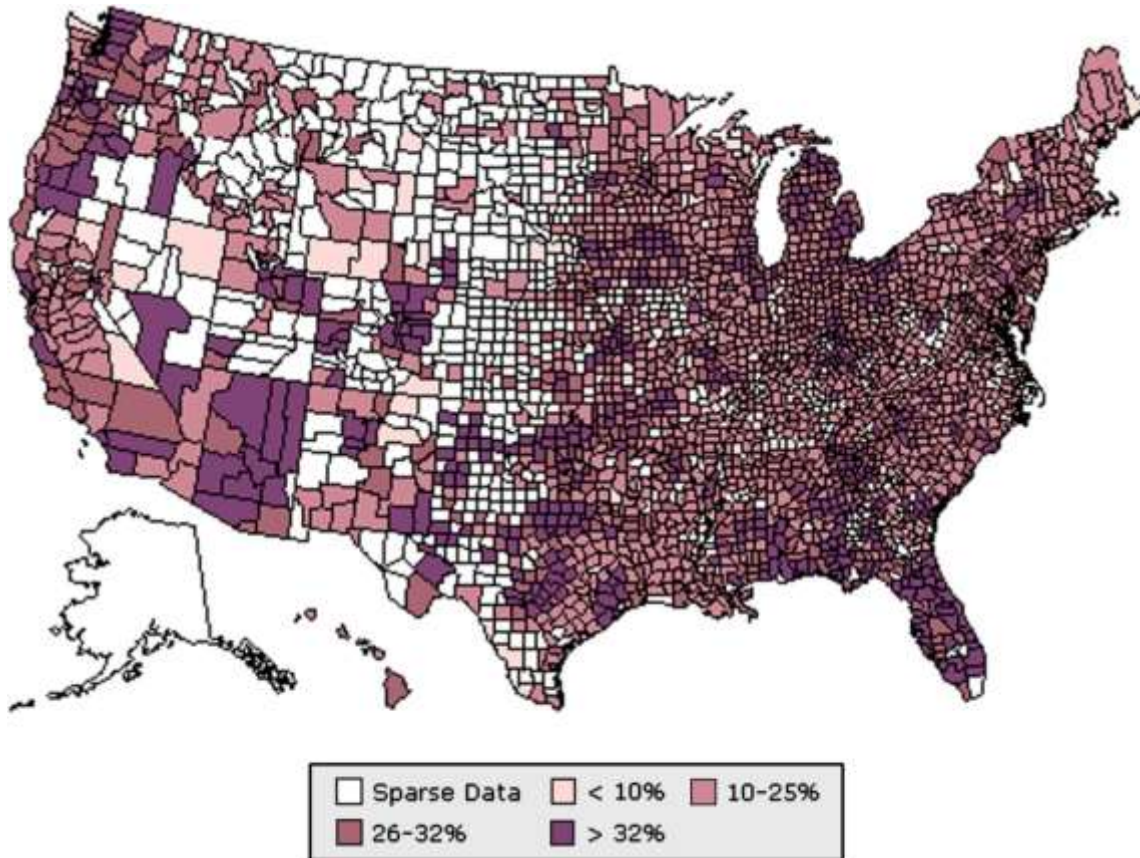
Geographically, hospice utilization rates were higher in the South and Southwest and lower in the Midwest and Northeast. States with the lowest hospice utilization included Alaska (8%), Maine (14%), South Dakota (16%), Wyoming (16%), and North Dakota (18%). These rates were consistent with other literature mentioned previously. Hospice utilization was highest in Arizona (49%), Colorado (45%), Florida (42%), and Nevada (37%).

State utilization rates were not discussed within the context of beneficiaries’ demographics. The authors noted that the older the individual, the more likely they were to use hospice. However, research did not explore the average or median age of hospice beneficiaries in states with either the highest or lowest utilization – a relationship that may have offered a more comprehensive understanding of factors influencing hospice utilization.

⁴ Cause of death was categorized as either heart disease, malignancy, CVA/Stroke, COPD, diabetes, sepsis, accident/fracture/suicide, influenza/pneumonia, Alzheimer’s disease, nephritis/kidney disease, or all other.

Figure 3 presented hospice utilization rates by county of residence for the entire descendant population in 2002. The authors identified that 967 of the 3,068 counties did not meet the standards of inclusion (primarily because of sample size). Beyond the map, there is no discussion of rurality or the influence population size may have had on hospice utilization.

Figure 3. Overall Hospice Utilization by County in 2002



Source: Connor, Elwert, Spence, & Christakis, 2007, Figure 3, p. 283.

Virnig, B., Haijun, M., Hartman, L., Moscovice, I., & Carlin, B. (2006). Access to home-based hospice care for rural populations: Identification of areas lacking service. *Journal of Palliative Medicine*, 9(6), 1292-1299.

Virnig et al. reviewed ZIP code level data (2000-2002) to identify and characterize those areas served and not served by a Medicare certified hospice. This research employed the United States Department of Agriculture's 2003 classifications of urban influence, and discussed the results within the lens of metropolitan, rural adjacent, and rural nonadjacent communities.

The study found that 2,900 ZIP codes in the U.S. were not served by a hospice and the availability of care was strongly correlated with the level of urban influence. See Table 12. Researchers estimated that 15,000 Medicare beneficiaries (age 65 or older) died annually without the opportunity to receive hospice care; however, this was less than 1% of the total deaths of Medicare beneficiaries in 2002.

Table 12. Medicare Deaths and Enrollees in Unserved Areas by Urban Influence

	Number of Elderly Living in Unserved Areas		Annual Deaths Occurring in Unserved Areas	
		%		%
Metropolitan	23,847	0.1%	1,016	0.1%
Large metro area, \geq 1 million	0	0%	0	0%
Small metro area, > 1 million	23,847	0.2%	1,016	0.2%
Rural adjacent	113,372	1.9%	5,201	1.9%
Micropolitan (urban cluster of at least 10,000) adjacent to large metro	4,908	0.6%	202	0.5%
Noncore (not micropolitan) adjacent to large metro	11,651	2.4%	594	2.4%
Micropolitan (urban cluster of at least 10,000) adjacent to small metro	29,655	1.2%	1,338	1.1%
Noncore (not micropolitan) adjacent to small metro with own town of at least 2500	41,649	2.9%	1,913	2.6%
Noncore (not micropolitan) adjacent to small metro with no own town of at least 2500	25,509	7.8%	1,155	6.9%
Rural nonadjacent	195,108	7.4%	9,181	6.7%
Micropolitan (urban cluster of at least 10,000) not adjacent to a metro area	42,749	3.2%	1,961	2.9%
Noncore (not micropolitan) adjacent to micro with own town of at least 2500	27,017	5%	1,323	4.6%

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	Number of Elderly Living in Unserved Areas		Annual Deaths Occurring in Unserved Areas	
		%		%
Noncore (not micropolitan) adjacent to micro with no own town of at least 2500	37,881	16.4%	1,806	15.1%
Noncore (not micropolitan) not adjacent to metro or micro with own town of at least 2500	33,405	8.9%	1,534	7.9%
Noncore (not micropolitan) not adjacent to metro or micro with no own town of at least 2500	54,056	30.9%	2,557	28.5%
Total	332,327	.9%	15,399	.9%

Source: Virnig et al., 2006, excerpt from Table 2, p. 1295.

Nationally, less than 1% of Medicare beneficiaries died in an underserved area; however, disparity of access was far more severe in predominantly rural states. Beneficiaries in Midwestern and Western states, with larger rural populations (e.g., South Dakota, Wyoming, and North Dakota) were more likely to have elderly living in areas not served by a Medicare certified hospice. See Table 13.

Table 13. Medicare Deaths and Enrollees by State in Unserved Areas

	Number of Elderly Living in Unserved Areas		Annual Deaths Occurring in Unserved Areas	
		%		%
South Dakota	26,760	23.9%	1,247	23.1%
North Dakota	19,724	20.5%	929	19.6%
Nebraska	18,690	7.9%	882	7.3%
Kansas	17,014	4.7%	874	4.6%
California	18,960	0.5%	866	0.5%
Montana	17,385	13.7%	838	13.4%
Washington	16,976	2.5%	750	2.2%
Alaska	17,327	44.1%	740	46.2%
Texas	14,620	0.7%	645	0.6%
Minnesota	11,930	1.9%	540	1.8%
Wyoming	11,332	18.4%	526	17.9%
Maine	9,029	4.7%	431	4.4%
Nevada	9,039	3.8%	410	3.8%
West Virginia	7,516	2.7%	398	2.5%
Missouri	8,217	1.1%	392	0.9%
New Mexico	8,380	3.9%	362	3.7%
Pennsylvania	6,325	0.3%	312	0.3%
Idaho	7,613	4.8%	300	3.2%
Tennessee	5,651	0.8%	298	0.8%
Iowa	6,034	1.4%	294	1.3%
Wisconsin	5,730	.8%	274	0.8%
Kentucky	5,177	1%	272	0.9%
Colorado	6,418	1.5%	269	1.3%
Arkansas	4,669	1.2%	264	1.3%
Vermont	5,697	7%	240	6%
Arizona	5,727	0.9%	203	0.7%

RURAL HOSPICE IN THE UNITED STATES

	Number of Elderly Living in Unserved Areas		Annual Deaths Occurring in Unserved Areas	
		%		%
North Carolina	3,656	0.4%	181	0.4%
Utah	4,189	2.1%	176	2%
Massachusetts	3,758	0.4%	158	0.3%
Virginia	3,378	0.4%	156	0.4%
Oklahoma	3,193	0.7%	151	0.6%
Illinois	3,472	0.2%	148	0.2%
Michigan	3,033	0.2%	142	0.2%
Indiana	2,970	0.4%	141	0.3%
New York	3,068	0.1%	127	0.1%
New Hampshire	2,182	1.4%	113	1.5%
Oregon	1,845	0.4%	86	0.4%
Louisiana	1,633	0.3%	74	0.3%
Georgia	1,181	0.1%	69	0.2%
Mississippi	1,104	0.3%	52	0.3%
Florida	665	< 0.1%	25	< 0.1%
Alabama	449	< 0.1%	21	< 0.1%
Hawaii	556	0.3%	20	0.3
Connecticut	0	0%	0	0%
D.C.	0	0%	0	0%
Delaware	0	0%	0	0%
Maryland	0	0%	0	0%
New Jersey	0	0%	0	0%
Ohio	0	0%	0	0%
Rhode Island	0	0%	0	0%
South Carolina	0	0%	0	0%

Source: Virnig et al., 2006, excerpt from Table 3, p. 1296.

The research team also presented the in-hospice death rate per 100 deaths for all areas, and only served areas (Table 14). This data showed little variation (regardless of urban influence code), indicating that areas served by a hospice did not have substantially higher in-hospice deaths than all areas. However, the study did not identify the in-hospice death rate among areas not served by a hospice.

Table 14. Impact of Hospice Availability on Hospice Use Rates

	In-Hospice Death Rate,* all Areas Included	In-Hospice Death Rate, only Served Areas Included
Metropolitan	27.4	27.4
Rural adjacent	21.4	21.7
Rural nonadjacent	18.8	19.6

* Per 100 deaths

Source: Virnig et al., 2006, Table 4, p. 1297.

Virnig et al. (2006) offered a much more comprehensive and detailed analysis of rural/urban hospice access than previous studies had by identifying hospice facility location through ZIP code files. However, while this study identified the number of deaths (among Medicare beneficiaries age 65 or older) occurring in an unnerved area, it did not identify if those who had died were eligible for hospice care. Similarly, cause of death was not considered, meaning reviewed data included conditions and circumstances where death was rapid or unexpected (e.g., suicide, influenza, pneumonia, and stroke); situations in which access to hospice would have been irrelevant.

Casey, M., Moscovice, I., Virnig, B., & Durham, S. (2005). Providing hospice care in rural areas: Challenges and strategies. *American Journal of Hospice & Palliative Medicine*, 22(5), 363-368.

To identify the unique challenges faced by rural hospice providers, Casey et al. reviewed four hospices that were serving rural patients in 1999. The hospices selected for inclusion represented the three common rural models for hospice care⁵. They were chosen based on region, size, and age. The research team conducted two site visits and held interviews with: (a) members of hospice teams; (b) hospice patients; (c) patients' family members; (d) board members; (e) home health aides; and (f) volunteers. After results had been verified with each participating hospice⁶, the authors produced a report identifying the challenges to providing rural hospice care along with the strategies to overcome said challenges.

The three identified challenges were in relation to finance, hospice staffing, and care coordination/physician referrals. Medicare and insurance reimbursements were not sufficient to

⁵ The common models of hospice care included: (1) hospital-based (representing 35% of hospice care in rural communities); (2) free-standing (34%); and (3) home health agency-based hospices (31%).

⁶ Hospices included in the case study: (1) Kanabec County Public Health Hospice, Mora, MN; (2) Regional Hospice Services, Inc., Ashland, WI with satellite sites in Hayward and Spooner, WI, and Ironwood, MI; (3) Hospice of North Central Florida, Gainesville, FL with satellite sites in Chiefland, Lake City, Palatka, and Jacksonville, FL; (4) Lower Columbia Hospice, Astoria, OR.

cover the hospices' costs of care. This inadequacy of reimbursement required all four hospices to rely on fundraising and donations to support their operating expenses.

The distance traveled to patients' homes was cited as a financial burden. Hospices had to absorb the expense of the 120 mile roundtrip, as well as the staff time spent traveling. Travel time also limited staff availability to provide direct patient care. Medication costs were also a challenge for hospices serving rural patients. The authors observed that one of the hospices studied had been caring for a patient with "pain medication costs of \$3,000 per month – an amount equivalent to the entire per diem received for care of the patient" (p. 366).

Hospices that served rural areas, especially those that were not associated with a larger entity and had low service volumes faced the challenges of recruiting and retaining staff. Hospices are required to have staff available 24 hours a day, seven days a week which only compounded the issue. Solutions identified through the case studies were employing staff from parent agencies, or sharing staff across programs.

While all hospices were identified as having issues regarding referral practices, rural communities faced the challenge of physician shortage, which made it harder to meet the requirement of a physician's terminal diagnosis and hospice referral. It was also more difficult to coordinate patient care when there was only one provider for the entire community. The authors suggested building relationships and agreements with other providers in the health care market (e.g., nursing homes, home health agencies, and hospitals). These partnerships could improve care coordination, and reduce the workload of a single hospice provider.

This study was significantly dated, and not generalizable to all rural hospice programs. However, the in-depth analysis and interview of various individuals involved in hospice care illustrated that providers, patients, and families alike cite the same challenges that have been

addressed in larger-scale quantitative research on the topic. While some solutions were provided, the authors believed that the appropriate hospice model for any given rural community “would depend on the size, density, and demographic characteristics of the service area population” (p. 367).

Kaufman, J., & Forman, W. (2005). Hospice and palliative care: An educational intervention for healthcare professionals in a rural community. *American Journal of Hospice and Palliative Medicine*, 22(6), 415-418.

Kaufman and Forman developed an educational intervention in an attempt to increase hospice utilization in a rural community in New Mexico. Beneficiaries in Taos County, New Mexico experienced low hospice enrollment and were reported to have 82% of its residents living in a rural area in 1999 (less than 20 persons per square mile).

The intervention included a half day conference for nurses and related health care professionals, and a one hour grand rounds presentation for physicians. Content included a discussion of:

- a) the benefits of the hospice approach for patients, b) eligibility criteria, c) how to foster discussion about hospice care with patients and their families, d) how to advocate for patients who qualify for hospice services, and e) the role of hospice in caring for people at the end of life. (p. 416)

Physicians were also provided information on the advances in hospice care. The intervention reached 27 of the approximately 150 nurses working in Taos County, and five of the 20 physicians.

The authors compared hospice admission data, diagnosis, length-of-stay, and referral source for eligible hospice recipients in Taos County in the year prior to the intervention, and the

year following. Data were retrieved from the hospice/home health care agency and the New Mexico Department of Health County Health Profile.

The authors identified an increase in the hospice annual census of 85% ($p < 0.001$); an increase from 33 patients accessing hospice care in 1999, to 65 patients the year following the intervention. However, other research has shown that hospice use has continued to increase annually across geographies and patient demographics (e.g., NHPCO, 2011; 2012). The researchers did not control for other confounding variables, nor did they discuss any national trends in either overall hospice utilization, or rural hospice utilization over the same period of time.

The authors did not find a change in the length-of-stay among hospice beneficiaries, and the diagnoses leading to hospice admissions were unchanged. The significant increase in hospice enrollment was found to have been the result of nursing home referrals. However, the article did not address the place of employment among training participants; it is unknown if the nursing staff or physicians that received the education were employed in a nursing home.

Though there were significant shortcomings in the report, the authors were able to identify a feasible educational intervention that may influence rural hospice utilization. The intervention was “inexpensive, locally run, and effective” at increasing hospice referrals among nursing homes (p. 418). However, the intervention did not result in increased or earlier referrals among physicians, which implied the need to tailor the education or identify a different population of focus.

Virnig, B., Moscovice, I., Durham, S., & Casey, M. (2004). Do rural elders have limited access to Medicare hospice services? *Journal of the American Geriatrics Society*, 52(5), 731-735.

Virnig, Moscovice, Durham, and Casey identified disproportionate Medicare hospice reimbursement rates between urban and rural providers in Minnesota in 2002. Hennepin County, an urban area, had been receiving a daily payment of \$108.65 for routine home care while Morrison County (rural) was being reimbursed at \$93.48 for the same level of care. While hospice reimbursements are adjusted using the hospice wage index, the rates are not adjusted for factors that result in higher costs among rural providers (e.g., increased travel, mileage, staff time, and benefit from economies of scale in purchasing supplies and/or pharmaceuticals). The research team then sought to identify rural urban disparities in hospice care.

Using data from the 1999 100% Medicare denominator file, the 100% Medicare Provider Analysis and Review inpatient hospitalization file, the 100% hospice files, and the Provider of Services file, the authors identified in-hospice death rates, hospice use, and average hospice volume for both rural and urban hospices nationwide. Hospice location was determined by the hospice's county mailing address. Geographic variation was categorized through the Urban Influence Codes (Table 15). Beneficiaries were assigned their level of rurality based on their county of residents, not the county service was accessed. It may be that they had received hospice services from an urban hospice provider.

The rate of hospice use by the Medicare population in 1999 was associated with the rural urban status of the beneficiaries. The hospice use rate in the "most remote rural areas was only 56% of the rate in the most-urban areas" (p. 733). The statistical significance of this geographic variation was not mentioned. While hospice use varied by rurality, there was no association between the in-hospital death rate and the level of urban influence.

Table 15. Rate of In-Hospice Death by Urban Influence Code, 1999

	Hospice Deaths per 100 Beneficiary Deaths*
Urban	
Metro area, ≥ 1 million population	22.9
Metro area, < 1 million population	21.3
Rural Adjacent	
Adjacent to a large metro area, with a city of $\geq 10,000$	18.6
Adjacent to a large metro area, no city of $\geq 10,000$	17.9
Adjacent to a small metro area, with a city of $\geq 10,000$	16.6
Adjacent to a small metro area, no city of $\geq 10,000$	16.7
Rural nonadjacent	
Not adjacent to a metro area, with a city of $\geq 10,000$	16.3
Not adjacent to a metro area, with a city 2,500-9,999	15.0
Not adjacent to a metro area and no city or a city less than 2,500 population	12.9
* Individuals fee-for-service and manages care populations; adjusted for age, sex, and race.	
Source: Virnig, Moscovice, Durham, & Casey, 2004, excerpt from Table 1, p. 732.	

Physical presence of a hospice was associated with higher in-hospice deaths. In 1999, more than 66% of urban counties had a hospice while less than 33% of rural adjacent and rural nonadjacent had a hospice provider in their community. Hospices that were located in the rural adjacent and nonadjacent areas were more likely to be hospital based and have fewer than 50 patients annually. Urban hospices were more likely to be free-standing and only 13% had fewer than 50 patients annually.

Finally, the authors noted that a significant proportion of rural hospices had low patient volumes and reported a lower Medicare daily reimbursement than their urban counterparts. In 1999, 28% of rural nonadjacent hospices were low volume (average daily census ≤ 3 patients) compared with 15% of the rural adjacent hospice facilities, and 5% of those located in an urban area. Additionally, the overall median daily payment to hospices in 1999 was \$1,421 a day (across patients) while low-volume hospices (as defined above) had a median reimbursement of only \$163. These findings, along with identification that the low-volume hospices were predominantly rural, indicated that rural hospices faced significant financial instability with regard to hospice services.

Dunham, W., Bolden, J., & Kvale, E. (2003). Obstacles to the delivery of acceptable standards of care in rural home hospices. *American Journal of Hospice and Palliative Care*, 20(4), 259-261.

Dunham, Bolden, and Kvale recognized that meeting the objectives of hospice care were especially challenging in rural communities. To illustrate this point, they completed a case study on a single rural hospice beneficiary in a rural Alabama community in 2001.

The authors described the hospice located in Pell City, Alabama as a program that cares for beneficiaries spread over a four county area of rural communities. Some of the logistical issues facing rural hospice included the distance between patients and the central location of the hospice facility, the risk of fatigue and burnout among isolated staff, and lack of a 24-hour pharmacy making it impossible to access medications and/or services at a time of patient crisis. The research team also noted that, in this case study, some of the beneficiaries were as far as 90 miles from the primary location. The presented case demonstrated all identified challenges and the consequence of inadequate rural hospice care.

The case described a 52 year old who had been diagnosed with cancer in 2000 and referred to hospice on April 16, 2001. His sister moved in to his rural residence to be the primary care giver while both a physician and a hospice nurse completed home visits. He was located 37 miles from the hospice office. Both the nurse and physician had visited the patient on April 18, 2001. At 11:30 at night on April 19, 2001 the on call nurse was notified that the patient was in serious pain and experiencing shortness of breath. The nurse then arrived 50 minutes later to make an assessment.

The sister had accidentally spilled a portion of the pain medication and the patient remained in extreme distress, unable to lie down and having severe hallucinations. Both the hospice physician and the backup nurse in office tried to locate additional medications for the

experienced on call nurse to administer to the patient. However, there was no immediate access to a pharmacy, and the distance to the hospice office prohibited the nurse from traveling to retrieve an additional dose of pain medication. After 90 minutes (and less than four days in hospice care), the patient died “in the midst of extreme anguish” (p. 261). The suffering of the patient had caused psychological distress to the sister, and had prevented the beneficiary from receiving proper hospice care – symptom management to provide comfort and care to patients and their families at the beneficiaries’ end-of-life.

While the single case study did not provide data or generalizable results, it did illustrate and corroborate what quantitative research had reported regarding rural hospice care. The case especially exposed the consequence of inadequate access to medications and pharmacy services. While the Medicare Conditions of Participation require hospices to have core services (to include nursing and physician services, as well as drugs and biologicals) available 24 hours a day, seven days a week, this is seldom possible in rural communities.

Virnig, B., Kind, S., McBean, M., & Fisher, E. (2000). Geographic variation in hospice use prior to death. *Journal of the American Geriatric Society*, 48(9).

Although significantly dated, the research by Virnig, Kind, McBean, and Fisher was one of the first reports to examine national geographic variation in hospice use looking at, and controlling for, a variety of demographic variables and market factors. Using data from the 100% Medicare denominator file and the 100% Medicare hospice file for 1996, along with the Dartmouth Atlas of Health Care, the research team was able to identify: (a) patient demographics; (b) hospice use rates; (c) expenditures; (d) per capita reimbursements; (e) hospital beds per 1000 population; (f) physicians per 100,000 population; and (g) in-hospital death rates per 1000 population.

Adjusting for age, sex, and race, the median hospice use before death rate was 10.9 hospice users per 100 beneficiary deaths, with a range of 0 to 45.1 between hospital service areas (HSAs). Rates for hospice use were much higher among urban HSAs than rural. In 1996, urban HSAs averaged 15.6 hospice patients (per 100 beneficiary deaths) compared to only 11.4 in rural HSAs. ($p > 0.001$). Research also found that the rates of hospice use were positively correlated with the “Medicare HMO penetration rate, the number of hospital beds per capita, average area Medicare reimbursements, and physician availability” (2000).

The results are dated, and the rural/urban variation did not employ a common categorization of hospice services areas. However, this study was national in scope, controlled for a variety of confounding variables, and reported statistically significant differences between hospice use categories. The study corroborated what smaller, state-level research had found to date: urban areas with higher reimbursement rates and greater physician availability had higher hospice utilization before death. These variations remained after adjustment for patient demographic characteristics.

ADDITIONAL HOSPICE RESOURCES

National Hospice Organizations and Websites

American Hospice Foundation

<http://www.americanhospice.org/>

The American Hospice Foundation, a 501(c)(3) non-profit organization, supports programs that serve the needs of terminally ill and grieving individuals of all ages. The Foundation advances hospice concepts by: (a) training school professionals who work with grieving students; (b) educating employers and managers about the needs of grieving employees; (c) creating tools to help hospices reach out to their communities; (d) promoting improved hospice benefits in managed care organizations; and (e) initiating research on consumer needs and preferences in end-of-life care.

By forging partnerships at local and national levels, the foundation ensures that hospice care is available to many who might otherwise be underserved. Current initiatives include: (a) training workshops and materials on grieving children for educators; (b) employer outreach campaign to aid bereaved employees and their co-workers; (c) in-service programs for hospice and nursing home staff; and (d) tools for decision-making at the end of life for caregivers of the terminally ill (American Hospice Foundation).

Centers for Disease Control and Prevention: National Home and Hospice Care Survey

<http://www.cdc.gov/nchs/nhhcs.htm>

The 2007 National Home and Hospice Care Survey (NHHCS) is one in a continuing series of nationally representative sample surveys of U.S. home health and hospice agencies. It is designed to provide descriptive information on home health and hospice agencies, their staffs, their services, and their patients. NHHCS was first conducted in 1992 and was repeated in 1993, 1994, 1996, 1998, and 2000, and most recently in 2007 (CDC, National Home and Hospice Care Survey, 2007).

Centers for Medicare and Medicaid Services (CMS): Hospice Center

www.cms.gov

The CMS houses updated hospice statistics for calendar years 1998 to 2008. These data include the 20 most frequent diagnoses, the number of patients, average length of stay, and trends over time in length of stay, by diagnosis. For a one-stop resource web page focused on the informational needs and interests of Medicare Fee-for-Service (FFS) hospices, go to the CMS Hospice Center – <http://www.cms.gov/Center/Provider-Type/Hospice-Center.html>.

Center to Advance Palliative Care

www.capc.org

The Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness.

As the nation's leading resource for palliative care program development, CAPC offers comprehensive training for palliative care programs at every stage - from strategic planning and funding to operations and sustainability. CAPC provides seminars, audio conferences, tools, reference materials, a robust website, and the Palliative Care Leadership Centers™ (PCLC) - a major training and mentoring initiative. It also sponsors www.getpalliativecare.org, a website for patients and families.

CAPC is supported by Altman Foundation, Brookdale Foundation, Cambia Health Foundation, Cameron and Hayden Lord Foundation, The Donaghue Foundation, The Fan Fox and Leslie R. Samuels Foundation, The John A. Hartford Foundation, Livestrong, the Mill Park Foundation, The Olive Branch Fund, The Partnership for Palliative Care, Stavros Niarchos Foundation, and The Y.C. Ho/Helen and Michael Chiang Foundation (Center to Advance Palliative Care).

Hospice Foundation of America

www.hospicefoundation.org

Hospice Foundation of America provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. health care system and the role of hospice within it. Hospice Foundation of America meets its mission by conducting programs of professional development, public education and information, research, publications and health policy issues. Their programs for health care professionals assist those who cope either personally or professionally with terminal illness, death, and the process of grief, and are offered on a national or regional basis. The programs for the public assist individual consumers of health care who are coping with issues of caregiving, terminal illness, and grief. Hospice Foundation of America is supported by contributions from individuals and corporations, bequests, grants from foundations, gifts from associations, civic and fraternal groups, and through program-related income (Hospice Foundation of America).

International Association for Hospice and Palliative Care

<http://hospicecare.com/home/>

IAHPC is a global non-profit, charity organization dedicated to the promotion and development of palliative care. The mission of the association is to collaborate and work to improve the quality of life of patients with advanced life-threatening conditions and their families, by advancing hospice and palliative care programs, education, research, and favorable policies around the world. The vision of the organization is to help to increase and optimize the availability of and access to hospice and palliative care for patients and their families throughout the world (International Association for Hospice and Palliative Care).

National Association for Home Care and Hospice

<http://www.nahc.org/>

The National Association for Home Care & Hospice (NAHC) is a nonprofit organization that represents the nation's 33,000 home care and hospice organizations. NAHC also advocates for the more than two million nurses, therapists, aides and other caregivers employed by such organizations to provide in-home services to some 12 million Americans each year who are infirm, chronically ill, and disabled. Along with its advocacy, NAHC provides information to help its members maintain the highest quality of care and is committed to excellence in every respect (National Association for Home care and Hospice, 2013a).

National Hospice and Palliative Care Association

<http://www.nhpc.org/>

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones (National Hospice and Palliative Care Organization, 2013a).

Additional Hospice Research (No Rural Focus)

The following hospice articles did not present rural specific data and did not identify variation by geography. However, they were either the most recent articles regarding current trends in hospice services and care, or were referenced in a majority of literature on the topic.

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Rural Hospice Literature Reviews

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