

Rural Hospice in the United States:  
A Review of the Literature

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TABLE OF CONTENTS

INTRODUCTION ..... 3

LITERATURE REVIEW ..... 6

    Hospice Care in the United States ..... 9

        Eligibility ..... 10

        Certification of Medicare Hospices ..... 10

        Medicare Benefit Payment and Coverage ..... 11

        Hospice Quality Measures ..... 14

    Current Hospice Environment: Data from the 2013 NHPCO Report ..... 16

        Hospice Care, Access, and Utilization ..... 17

        Rural Hospice Care ..... 21

DISCUSSION ..... 28

REFERENCES ..... 30

## 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, 2013a). 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).

The payment rates for hospice are updated annually by the inpatient market basket index, but the methodology for determining the base rate for hospice care has not been recalibrated since the benefit's initiation in 1983. While hospice payment rates are adjusted geographically to account for differences in wage rates among local markets, the payment scale does not account for increased travel or distance of hospice providers from beneficiaries – an important

consideration for rural and frontier hospice care and reimbursement. Rural hospices cite higher costs for delivery of care related to travel, inadequate staff size, and the inability to benefit from economies of scale; yet, under the current reimbursement model, they are reimbursed at a lower rate when compared to urban hospices (Casey, Moscovice, Virnig, & Durham, 2005; MedPAC, 2013).

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).

In response to the lack of comprehensive rural hospice research, current health reform efforts, and the MedPAC's recommendation for revision to the current hospice payment methodology, the Office of Rural Health Policy (ORHP) charged the Rural Health Reform Policy Research Center (RHRPRC) with exploring the current environment of rural hospice care in the United States. Given the paucity of data regarding rural hospice, findings from this study

will help to inform MedPAC, CMS, and other stakeholders on rural specific hospice issues pertaining to new Medicare hospice reimbursement policies. The RHRPRC research team is using a mixed methods approach to examine the following issues impacting rural hospice services: access, utilization, reimbursement, and quality of care.

The quantitative analysis describes the utilization of hospice services by rural and urban Medicare beneficiaries' and examines differences in key measures, such as length of stay and live discharges. . The qualitative component supplements key quantitative research through structured interviews with rural and frontier hospice providers and national hospice experts, including CMS hospice policy staff and representatives from the National Hospice and Palliative Care Organization (NHPCO). The first year of the research project includes the following three components which explore the current environment of rural hospice services providing a comprehensive understanding of rural/urban hospice utilization, reimbursement, and current issues:

1. Qualitative study – Interview/survey of rural and frontier hospice chief executive officers (CEOs)
2. Qualitative study – Interview of rural hospice stakeholders
3. Quantitative study – Review of CMS claims data to examine rural and urban Medicare beneficiaries' utilization of hospice care

## LITERATURE REVIEW

The search for 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 utilization, access, 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

<b>Description of Services</b>	
<b>Hospice</b>	<ul style="list-style-type: none"> <li>• Patients are enrolled through a referral from the primary care physician and a hospice care provider.</li> <li>• The hospice program is overseen by a team of hospice professionals, and is administered in the home.</li> <li>• Hospice often relies upon the family caregiver, as well as a visiting hospice nurse.</li> <li>• 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.</li> <li>• 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.</li> </ul>
<b>Palliative Care</b>	<ul style="list-style-type: none"> <li>• Palliative care is a method of administering “comfort” care and increasingly, is offered most prevalently by hospitals.</li> <li>• 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.</li> <li>• 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.</li> <li>• 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.</li> <li>• 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.</li> </ul>
<b>Home Health Care &amp; Home Care</b>	<ul style="list-style-type: none"> <li>• Home Health Care and Home Care are both a form of home and community-based services (HCBS).</li> <li>• 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.</li> <li>• 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.</li> <li>• There is no requirement participants forgo curative treatment, or be in the last months of life.</li> <li>• <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.</li> <li>• <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.</li> </ul>

**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.

The following review begins with a discussion of the current structure of hospice services. It is this definition of hospice care that was applied when reviewing existing research on the topic. Characteristics of rural hospice are then presented, along with gaps in the current research; discussion is to follow.



### **Hospice Care in the United States**

During the 1982 enactment of the Tax Equity and Fiscal Responsibility Act (TERFRA), Congress institutionalized hospice care as a Medicare Benefit (Federal Register, 2012; Hospice Association of America (HAA), 2010; MedPAC, 2012). Hospice was, and continues to be, defined as “a program of care and support for people who are terminally ill” (Centers for Medicaid & Medicare Services (CMS), 2013b, p. 4). The hospice benefit provides comfort and support services to manage the physical, psychological, social, spiritual, and practical issues that may arise during the dying process (CMS, 2013b; HAA, 2010). The program considers both patient and family as a single unit of care with additional counseling services for the family during the one year bereavement period following the death of a hospice beneficiary (Federal Register, 2012).

Hospice care is provided by an interdisciplinary team of professionals which may include physicians, nurses, counselors, social workers, physical and occupation therapists, speech-language pathologists, hospice aides, homemakers, and/or volunteers (CMS, 2013b; HAA, 2010; MedPAC, 2012; 2013). While care may occur in a hospital, long term care facility, nursing home, free-standing hospice house, or a hospice inpatient facility, MedPAC (2013) reported 97.1% of hospice care days occurred in the primary residence of the beneficiary in 2012. As a result of high rates of care occurring in the home, a beneficiary’s family member typically serves as the primary caregiver. Members of the hospice team make regular visits to monitor the patient and provide other services as needed (National Hospice and Palliative Care Organization (NHPCO), 2012). The hospice nurse and physician are also available by phone 24 hours a day, seven days a week – a requirement for Medicare hospice certification.

## **Eligibility**

To be eligible, a beneficiary's hospice physician and attending physician must certify that he or she has a life expectancy of six months or less if the illness were to run its predicted course. Additionally, the beneficiary must "elect" the Medicare hospice benefit and agree to forgo intensive conventional treatment for the terminal disease. Although a beneficiary must have a certified life expectancy of six months or less, the patient may remain in hospice care over an extended period of time. The Medicare Payment Advisory Commission (MedPAC) notes that:

If the patient's terminal illness continues to engender the likelihood of death within six months, the patient can be recertified for another 90 days. After the second 90-day period, the patient can be recertified for an unlimited number of 60- day periods, as long as he or she remains eligible. For recertification, only the hospice physician has to certify that the beneficiary's life expectancy is [still] six months or less. (2012, p. 283)

Hospice services are primarily provided in the home of the beneficiary; however, services may be utilized in a hospital, long term care facility, nursing home, free-standing hospice house, or a hospice inpatient facility (CMS, 2013b; Chung & Burke, 2012). An individual must ensure they receive care from a Medicare-approved hospice program in order to receive the Medicare hospice benefit (CMS, 2013b; MedPAC, 2012; 2013). Not all hospice programs are approved for reimbursement under Medicare, though the NHPCO reported that 93.1% of hospices in the United States were certified in 2012 (2013). Hospice programs are accountable to state licensing agencies and must adhere to federal regulations.

## **Certification of Medicare Hospices**

Organizations providing hospice care must be certified by State agencies (contracted to conduct a survey of hospices through CMS) and meet the minimum participation standards as

prescribed by CMS (Office of Inspector General (OIG) & Levinson, 2007). Much like other health care entities, hospices must comply with CMS Conditions of Participation (COPs). The most recent regulatory update to the hospice COPs was published in 2008 in volume 73 of the Federal Register (Federal Register, 2008).

In order to renew their license, hospices must undergo recertification through their State agency. However, there are no regulations which specify the frequency of a state survey (required for recertification) with most hospices undergoing recertification every six to eight years. This frequency is far less than the recertification requirements of nursing homes, hospitals, and home health agencies which are surveyed every one to three years (OIG & Levinson, 2007).

### **Medicare Benefit Payment and Coverage**

The Centers for Medicare and Medicaid Services (CMS) is a branch of the United States Department of Health and Human Services and is responsible for administering the Medicare hospice care benefit. Under Medicare Part A, hospice providers are paid a daily rate for each beneficiary enrolled in their program. Payments are made according to a fee schedule that delineates between four hospice care categories: (1) routine home care; (2) continuous home care; (3) inpatient respite care; and (4) general inpatient care (GIP). See Table 2 for a description of each care category and the associated base payment rate for fiscal year 2012. MedPAC reported that routine home care accounted for 97.1% of hospice care days in 2012 (2013).

Table 2. Medicare Hospice Payment Categories and Rates, FY 2012

Category	Description	Base Payment Rate
Routine Home Care	Home care provided on a typical day	\$151/day
Continuous Home Care	Home care provided during periods of patient crisis	\$36.73/hour*
Inpatient Respite Care	Inpatient care for a short period to provide respite for primary caregiver	\$156/day
General Inpatient (GIP) Care	Inpatient care to treat symptoms that cannot be managed in another setting	\$672/day

\* MedPAC states that payment for continuous home care (CHC) is an hourly rate for care delivered during periods of crisis if care is provided in the home for 8 or more hours within a 24-hour period beginning at midnight. A nurse must deliver more than half of the hours of this care to qualify for CHC-level payment. The minimum daily payment rate at the CHC level is \$294 per day (8 hours at \$36.73 per hour); maximum daily payment at the CHC level is \$881 per day (24 hours at \$36.73 per hour).

**Source:** MedPAC, 2012, Table 11-1, p. 284.

The hospice assumes financial responsibility for all services associated with their patients' care to include pharmacy, emergency room visits, and visits to other physicians' offices. The hospice program receives daily compensation for an individual enrolled regardless of whether hospice staff were contacted, or made a visit to the given beneficiary on that day.

This payment design was adopted to:

encompass not only the cost of visits but also other costs a hospice incurs related to on-call services, care planning, drugs, medical equipment, and supplies related to the patient's terminal condition; patient transportation between sites of care specified in the plan of care; and other less frequently used services. (MedPAC, 2012)

The Medicare hospice benefit covers a range of services. Reimbursed care may include: (a) medical appliances and supplies; (b) physician services; (c) nursing care; (d) counseling and social work services; (e) short-term inpatient care (respite care); (f) homemaker and home health aide services; (g) drugs and biologicals for symptom management and pain relief; (h) spiritual care; (i) bereavement services; and (j) physical, occupational, and/or speech therapy (MedPAC, 2012; NHPCO, 2012; 2013).

Medicare covers the entirety of hospice care on behalf of the beneficiary and there is no deductible. Once enrolled in hospice, and covered by Medicare Part A, patients are no longer eligible for Medicare Part D (prescription drug coverage). Under hospice care the patient is responsible for no more than five dollars for each prescription drug or other product for pain relief and symptom control, and they are required to cover only five percent of the Medicare-approved amount for inpatient respite care<sup>1</sup> if needed. All other expenses are absorbed by the hospice agency.

MedPAC has made several suggestions for revision to the current system of reimbursement. These suggestions have been made, in a large part, as a result of research that illustrates the disparity in payment. Casey, Moscovice, Virnig, and Durham (2005) stated that per diem rates were lower for rural hospices as a result of adjustments related to the hospice wage index. However, the rates were not adjusted to account for differences in costs that are significantly higher for rural hospices, such as travel to patients' homes, physician time, staffing for a small population of hospice patients, and economies of scale.

Critical access hospitals (CAHs) face an additional challenge with regard to hospice reimbursement. CMS reports that "A CAH may also be granted "swing-bed" approval to provide post-hospital Skilled Nursing Facility-level care in its inpatient beds" to include hospice care. In this instance, a hospice contracts with a participating CAH and "the CAH negotiates reimbursement through an agreement with the hospice" (CMS, 2013a). The CAH uses an available swing-bed to provide hospice care at a reduced rate of reimbursement. CMS states that "The CAH may dedicate beds to the hospice, but the beds must be counted toward the 25-bed maximum. However, the hospice patient is not included in the calculation of the 96-hour annual

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<sup>1</sup> Respite care refers to inpatient hospice care in a Medicare-approved facility (such as a hospice inpatient facility, hospital, or nursing home), lasting no longer than five days. The intent of respite care is to provide rest for the primary caregiver (family member).

average length of stay” (CMS, 2013a). This payment structure, along with the aforementioned barriers identified for rural hospices makes providing end-of-life care difficult, and expensive, for CAHs.

### **Hospice Quality Measures**

CMS ensures that Medicare-approved hospices meet federal regulations, and under the Patient Protection and Affordable Care Act of 2010 (Affordable Care Act), will now also ensure hospice programs are reporting data on quality of care. Many health care entities have been required to report on a variety of quality measures through certification or reimbursement policies for several years. Hospice and palliative care organizations will be required to participate in similar CMS quality reporting beginning in 2014.

In 2001, leaders in hospice and palliative care met to discuss improving the quality of end-of-life services, forming the National Consensus Project for Quality Palliative Care (NCP). The first goal of the group had been to develop core concepts and structure for quality, which included eight domains of practice<sup>2</sup>. The *NCP Clinical Practice Guidelines for Quality Palliative Care* addressed palliative care across multiple disciplines and continues to be revised each year with recommendations for quality hospice services (Carlson et al., 2011; NCP, 2013).

In 2006, the National Quality Forum (NQF) adopted the guidelines proposed by the NCP and identified a set of preferred practices for quality hospice care. Hospice services were also identified as a national priority area for health care quality improvement (Carlson et al., 2011). The NQF’s endorsement of the *NCP Clinical Practice Guidelines* established areas within which hospices were to develop outcome measures for their palliative care programs (NCP, 2013).

The Affordable Care Act directed CMS to implement “an annual quality reporting

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<sup>2</sup> NCP eight domains of practice: (1) physical aspects of care; (2) psychological and psychiatric aspects of care; (3) social aspects of care; (4) spiritual, religious, and existential aspects of care; (5) cultural aspects of care; (6) care of the imminently dying patient; (7) ethical and legal aspects of care; and (8) structures and process of care.

program for hospice organizations, beginning in 2013 that includes a financial incentive for hospice provider participation” (NCP, 2013, p. 8). CMS must identify and require measures that have been nationally endorsed; however, they may specify measures that have not been endorsed if they are determined appropriate by the Secretary (CMS, 2013c).

To meet the quality reporting requirements for fiscal year 2014, hospice providers must report on two measures: (1) a structural measure related to the content of the hospices’ Quality Assessment and Performance Improvement (QAPI) program<sup>3</sup>; and (2) the National Quality Forum Pain Measure (#0209) (CMS, 2013c; 2013d). CMS states that “for fiscal year 2014, and each subsequent year, failure to submit required quality data shall result in a 2 percentage point reduction to the market basket percentage increase for that fiscal year” (2013c). Currently, all hospice providers that were Medicare Certified as of October 2012 are required to collect and submit quality data to CMS (CMS, 2013d).

While required quality data collection is new to hospices, hospice organizations and facilities have been voluntarily striving to provide and improve quality of care for over a decade. As an example, NHPCO has been collecting quality data through a variety of tools, three of which address quality of care. The collected data, and subsequent reports, are used by hospices to review current care and to improve care provided.

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<sup>3</sup> For more information on QAPI, references the CMS User Guide for Hospice Quality Reporting Data Collection (2013), or QAPI: A New Way to Manage Hospice Quality published in 2007 by OCS.

Table 3. NHPCO Performance Measure Surveys/Reports

Performance Measures	NHPCO Description	Data Submission and Reports
<b>Patient Outcome Measures (POM)</b>	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"> <li>• Hospice programs submit data quarterly into DART*</li> <li>• Reports available to NHPCO members the 1<sup>st</sup> of June, September, December, and March</li> </ul>
<b>Family Evaluation of Hospice Care (FEHC)</b>	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"> <li>• Hospice programs submit data quarterly into DART*</li> <li>• Reports available to NHPCA members the 1<sup>st</sup> of May, August, November, and February</li> </ul>
<b>Family Evaluation of Bereavement Services (FEBS)</b>	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"> <li>• Hospice programs submit data bi-annually into DART*</li> <li>• Reports available to NHPCA members August 1, and February 1</li> </ul>

\*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.

### Current Hospice Environment: Data from the 2013 NHPCO Report

While CMS and state health departments track licensure and regulation compliance and insurers/payers compile patient specific data, several other groups conduct research, provide information, and advocate for hospice care. The following discussion presents the current landscape of hospice care as described through the data collected by one of the nation's leading hospice organizations.

The NHPCO is the largest nonprofit membership organization for hospice and palliative care programs and professionals in the United States (NHPCO, 2013b). 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 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). The NDS includes program, patient, process, and financial statistics and is considered a comprehensive compilation of hospice trends in the U.S. NDS data is voluntarily self-reported by active hospice providers and includes hospice organizations that are not members of the NHPCO. Although the NHPCO's data are derived from a convenience sample, the estimates have been found reliable and accurate.

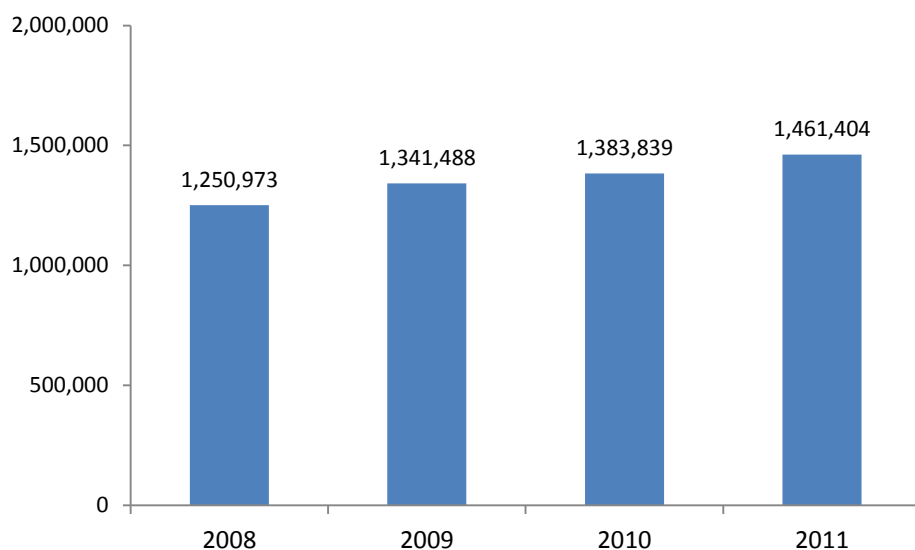
The NHPCO data are used to answer the following four questions related to hospice care: (1) who provides hospice care?; (2) who are the patients cared for by hospice?; (3) how much and what kind of services do hospice patients and their families receive?; (4) how much money does hospice cost (NHPCO, 2013c)? Data are reported at the national level and hospice care variables are stratified by agency type, patient level of care, and/or payer mix; however, data is not stratified by rurality.

### **Hospice Care, Access, and Utilization**

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 gradually increasing (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 the percentage has not been determined for 2012, NHPCO reported 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 percentage 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 4 identifies an increase in the percent of agencies that were part of a nursing home between 2010 and 2011 (NHPCO, 2011; 2012; 2013).

Table 4. NHPCO: Agency Type by Year

<b>Agency Type</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
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 5.

Table 5. NHPCO: Location of Hospice Patients at Death by Year

<b>LOCATION OF DEATH</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
<b>Patient's Place of Residence</b>	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%
<b>Hospice Inpatient Facility</b>	21.2%	21.9%	26.1%	27.4%
<b>Acute Care Hospital</b>	10.1%	11.4%	7.4%	6.6%

**Source:** NHPCO, 2011; 2012.

While 2011 estimates presented a substantial increase in the number of hospice agencies associated with a nursing home with 2012 estimates unchanged (Table 4), the percentage of hospice patients dying in a nursing home remained largely unchanged (Table 5). The NHPCO offers no explanation.

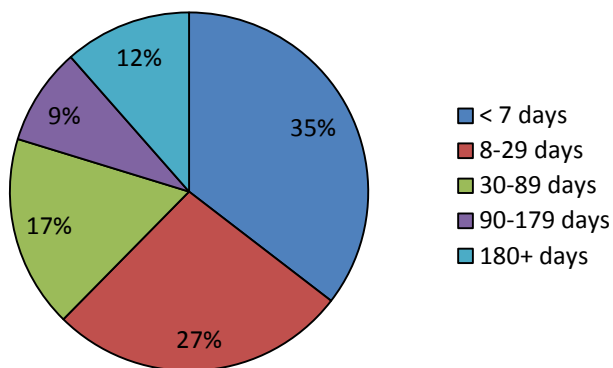
Hospice agencies range in their staff clinical knowledge/experience and size. Agency size may be categorized using total admissions over a 12-month period or daily census. In 2012, 77.4% of hospice agencies had fewer than 500 total admissions per year. The average daily census across all agency types 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, an increase from 71 patients 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 days in 2011), while the average was 71.8 days (up from 69.1 days 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 by rurality.

### Rural Hospice Care

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 the classification of rurality may be unreliable or inconsistent as it was a result of individual reporting.

There are other organizations in addition to the NHPCO that conduct research around hospice care. For example, the National Association for Home Care & Hospice, the Hospice Association of America (HAA), and the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS) also complete reports regarding hospice care. However, these reports do not have a rural focus.

MedPAC is an independent Congressional agency established to advise the U.S. Congress on issues impacting the Medicare system. In chapter five of their recent *Report to Congress*, MedPAC made recommendations on the current hospice reimbursement system with regard to costs at the beginning and end of an episode. With regard to rural care, if payments were adjusted to be more in-line with the cost of hospice care at the beginning and end of a hospice episode, rural hospices would “see their aggregate payments increase by 1.0 percent” (MedPAC, 2013, p.129). The 2013 report did not address rural hospice care beyond this notation; however, the 2012 MedPAC Report to Congress did offer characteristics of rural hospice services.

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 comment on hospice utilization among urban and rural beneficiaries. Instead, MedPAC wrote that use rates for beneficiaries in

the five geographic<sup>4</sup> 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 received by rural and urban Medicare beneficiaries.

Table 6 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 the following locations: 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. The discussion does not address utilization of a hospice by the organizations’ locations. Specifically, an increase in utilization of hospice services among rural, adjacent to urban residents may be the result of increased utilization of urban hospice services.

Table 6. 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.

<sup>4</sup> 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.

The most recent data illustrates a consistent increase in the number of hospice providers nationwide (MedPAC, 2013a). Between 2000 and 2009, the number of hospice providers increased by 53%; the increase in providers was evident 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% (MedAPC, 2012). Additionally, rural areas experienced a 1% decline in the number of hospice providers between 2009 and 2010 while urban hospices increased access by an additional 5% (MedPAC, 2012).

In summary, the MedPAC report did not address the results as an indicator of disproportionate hospice care between urban and rural Medicare beneficiaries, 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 to local hospice services in rural and frontier communities, assuming that increased services in urban locations are meeting the needs of rural and frontier Medicare beneficiaries.

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. Other variables, such as Medicare payments and providers' costs, included rural and urban stratifications.

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 7 for the rural and urban hospice margins from 2003 through 2009.

Table 7. Rural and Urban Hospice Medicare Margins, 2003-2009

	<b>Percentage of Hospices 2009</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>
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 7) had lower margins than those serving urban residents, margins did not decrease as the degree of rurality increased (see Table 8). Hospices serving frontier beneficiaries actually reported higher Medicare margins than those hospices serving urban residents.

Table 8. Medicare Margins by Type of County Served, 2009

<b>Hospice Provider by Predominant Type of County Served</b>	<b>Aggregate Medicare Margin</b>	<b>Percent of Hospices</b>
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 2012 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 access or utilization of care; rather, the MedPAC focused on the growth of access and utilization across geographies.

Additional research related to rural hospice care is significantly dated and does not use a standard measure or categorization of rurality. However, the data consistently pointed to 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).

In 2002, 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 (Virnig, Haijun, Hartman, Moscovice, & Carlin, 2006). Virnig et al. (2006) also reported that 15,000 Medicare beneficiaries (age 65 or older) died without the opportunity to receive hospice care in 2002. Connor, Elwert, Spencm, and Christakis, (2007) identified a similar trend in rural hospice utilization, stating that the states with the lowest hospice utilization in 2002 included Alaska (8%), Maine (14%), South Dakota (16%), Wyoming (16%), and North Dakota (18%).

Utilization of hospice services has long been linked to access to hospice care. Historically, research consistently highlighted insufficient access to hospices services among rural beneficiaries. In 1999, physical presence of a hospice was associated with higher in-hospice deaths. In that year, 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 (Virnig,

Moscovice, Durham, & Casey, 2004). As a result of inadequate access, Virnig et al. (2004) reported that the hospice use rate in the “most remote rural areas was only 56% of the rate in the most-urban areas” (p.733). Older data also identified that urban areas with higher reimbursement rates and greater physician availability had higher hospice utilization before death. These variations remained constant after adjustment for patient demographic characteristics (Virnig, Haijun, Hartman, Moscovice, & Carlin, 2000).

Although they were working with a different conceptualization of rurality, Campbell, Merwin and Yan (2009) reported in 2005, that the percentage of counties with at least one certified hospice was much higher in metro areas (59%) than in nonmetro adjacent (39%) and rural (36%). Campbell and colleagues’ research also noted that 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 average rate of physicians had a direct effect on the availability of hospice services; 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).

Temkin-Greener, Zheng, and Mukamel corroborated this finding in 2012 when they reported that there was a statistically significant difference in the average number of hospice providers in urban (9.6 providers) and isolated rural (.55 providers) communities in 2007. In the same year (2007), Chung and Burke found only 4% of hospice agencies were located in rural areas.

## DISCUSSION

Rural hospice care has been largely removed from the literature with a focus, instead, on length-of-stay and cost-savings of hospice services across all geographic locations. When rurality is stratified, the categories of rurality are often inconsistent, as are the data sources. Additionally, much of the discussions around geographic variation have only gone as far as county-level data with several cases missing, or have explored hospice use and access rates by state or region of the U.S. Reviewing county-level data does not identify all underserved areas as a county may be quite large and have variable availability to hospice services.

Regardless of the rural/urban classification employed, studies have identified variation in access and utilization to hospice services. While the data illustrate that hospice services are less accessible and underutilized among rural populations, a majority of the studies are dated or refer to only a single or small set of diagnoses.

Past research has also explored rural hospice access either exclusively from the rurality of the patient, or the rural/urban status of the facility. Furthermore, studies regarding hospice use have done the same; measuring either the rate of hospice use between rural and urban beneficiaries, or rate of use among rural and urban facilities. Regardless of the studies' foci (e.g., facility location or patients' primary residence), studying either rural or urban status exclusively limits the generalizability of the findings and policy recommendations.

While access and utilization have both been discussed in the research, they were not often addressed collectively. Though dated, Virnig et al. (2006) explored the relationship between access and use and identified that lack of hospice availability in rural communities could not explain the urban/rural gradient in hospice use prior to death – a topic worth further consideration.

## RURAL HOSPICE IN THE UNITED STATES

In recognition of the paucity of current rural hospice research, health reform efforts, and MedPAC's recommendation for revision of the current hospice payment methodology, the Office of Rural Health Policy (ORHP) charged the Rural Health Reform Policy Research Center (RHRPRC) with exploring the current environment of rural hospice care in the United States.

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