Availability of Hospice in Rural Pennsylvania

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Executive Summary

This research focused on the availability of palliative care – specifically hospice care – in rural Pennsylvania. Palliative care is defined as, "patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering," and is delivered "throughout the continuum of illness to address physical, intellectual, emotional, social, and spiritual needs, and to facilitate patient autonomy, access to information, and choice."

Under this guiding definition, hospice represents a specific form of palliative care that is typically delivered within the last six months of life. There is a strong evidence base that demonstrates the benefits that hospice has on quality of life and cost of care at patients' end of life. Despite these reported benefits, hospice remains underused, with substantial geographic variation in hospice availability and use rates.

This research analyzed data from the Centers for Medicare and Medicaid to describe the availability and use of hospice care throughout Pennsylvania. Specifically, the research: describes the distribution of hospices and the number of hospices providing care to rural Pennsylvania counties compared to urban counties; developed a descriptive profile of rural Pennsylvania's hospice users and drew comparisons between rural and urban Pennsylvania counties; analyzed patient use information to project the number of future hospice users in Pennsylvania counties; and analyzed information collected from semi-structured interviews with hospice and palliative care providers and administrators to understand the challenges and opportunities for key stakeholders – those individuals providing hospice and palliative care.

The analyses yielded a number of important findings:

- In Pennsylvania, there was a 4.7 percent decrease in the number of hospice providers from 2017 to 2019, with a 5.3 percent decrease in rural counties and a 4.5 percent decrease in urban counties.
- About 52 percent of rural hospices are nonprofit, most of which are home health agency-based, and 48 percent are for-profit, most of which are free-standing. The facility types have implications for how care can be delivered – home-based hospice care requires substantial travel time to a patient's place of residence for hospice staff, adding to overhead costs for hospices and delaying care for patients residing far from the hospice facility.
- Several rural counties are served by only a single hospice provider, and, in 15 counties, there is no hospice provider physically located in the county, further highlighting access issues related to travel time for hospice staff or patients/families.
- Generally, the research found lower hospice use rates for rural patients. However, the research indicated that in both rural and urban areas, patients who were female, white, age 85 or older, and Medicare Advantage beneficiaries had higher rates of hospice use.
- The research found that, from 2006 to 2016, Medicare hospice use rates increased in every county except two. Most counties saw double-digit percent increases.
- Assuming similar patterns of hospice use, the research found that there will be significant increases in future hospice demand, based on projections of an aging population in rural Pennsylvania counties. This is of particular importance to researchers and policymakers as the results of the study interviews suggest that rural

Pennsylvania hospices are already experiencing substantial staffing and provider shortages. Therefore, these staffing and provider shortages may be exacerbated by increasing demand.

- Interviews with stakeholders – namely hospice care providers in rural Pennsylvania – validated hospice availability and use concerns related to travel time, and lack of choice for patients and families. They also highlighted issues related to using electronic health records in areas with poor internet or cell service.

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INTRODUCTION

This research focused on the availability of palliative care – specifically hospice care – in rural Pennsylvania. According to the National Consensus Project for Quality Palliative Care (NHPCO), palliative care is defined as, "patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering," and is delivered "throughout the continuum of illness to address physical, intellectual, emotional, social, and spiritual needs, and to facilitate patient autonomy, access to information, and choice" (NHPCO, 2013). Under this guiding definition, hospice represents a specific form of palliative care that is typically delivered within the last six months of a patient's life (NHPCO, 2018). Reports of hospice availability and use are often based on national-level analyses, such as the Medicare Payment Advisory Commission's (MedPAC) annual reports to congress or the National Hospice and Palliative Care Organization (NHPCO) annual reports (NHPCO, 2018; MedPAC, 2019). These national-level analyses do not address important contextual differences that exist between or within states (e.g., population density, population sociodemographic and health characteristics, and distribution of healthcare resources). Therefore, little is known about hospice availability and use within Pennsylvania, and in particular within rural Pennsylvania.

Hospice availability. The availability of hospice is an important indicator of an individual's ability to access hospice care and is associated with hospice use, (Virnig, Moscovice, Durham, & Casey, 2004). National-level analyses of hospice availability have demonstrated that the availability of hospice care varies geographically and is associated with socioeconomic characteristics of a county (Silveria et al., 2011; Virnig, Moscovice, Durham, & Casey, 2004; Wang et al., 2015). The researchers did not find any recent analyses of hospice availability within rural Pennsylvania.

Hospice utilization. National analyses of hospice use revealed that current state-level rates of hospice use among elderly (age 65 years and older) decedents (individuals who have died) ranged from 23 percent to 58 percent (NHPCO, 2018; MedPAC, 2019). However, much less is known about county-level hospice use among decedents, and in particular those living in rural Pennsylvania, as most of the current understanding of county-level hospice utilization comes from national-level analyses (Silveria et al., 2011; Virnig, Moscovice, Durham, & Casey, 2004; Wang et al., 2015). While publicly available county-level datasets, such as the Center for Medicare and Medicaid's (CMS) Public Use File, report county-level hospice use within Pennsylvania, the hospice utilization rate is measured among *all* Medicare beneficiaries in a county rather than only among beneficiaries that died in a given year (decedents; CMS, 2019). However, hospice use is best measured as the number of hospice users within the population of *decedents*, or those individuals who have died, rather than among a population as a whole, as hospice use rates among an entire population can be influenced by the age structure of a population and the mortality rate (i.e. would expect hospice to be concentrated among those who die within a given year) (Connor, Elwert, Spence, & Christakis, 2007; MedPAC, 2019; Virnig, Moscovice, Durham, & Casey, 2004; Wang et al., 2015).

As a result, scholars and policymakers currently have limited information about hospice availability and use in rural Pennsylvania. Such information is necessary to develop state and local policies that address the needs of individuals and families requiring hospice care across the Commonwealth. This research intended to address this gap and contribute to further research and development of policies pertaining to hospice care access within Pennsylvania.

Therefore, the purpose of this research was to examine how hospice availability and use varies across Pennsylvania, and whether any contextual factors – particularly in rural areas – may be contributing to these differences.

The following analyses of hospice availability and use are guided by existing academic and professional literature. Within this literature, several key points motivate and inform this study. First, it is common to distinguish between palliative and hospice care. The broad definition of palliative care makes it difficult to measure at the population level (Casarett & Teno, 2016; Schenker & Arnold, 2015). Further complicating population-level measures of palliative care is that many treatments may be both palliative and curative. For example, chemotherapy in cancer care could be used with the intention to cure the cancer *or* as a treatment used solely with the intention to palliate, or lessen the pain and symptoms associated with the cancer, with the knowledge that the treatment will not cure the cancer (e.g., using chemotherapy to reduce a cancerous mass in the context of metastases; Neugut & Prigerson, 2017). Thus, the intent of a treatment or procedure is not possible to identify in population-level data. We therefore address these issues in palliative care measurement by focusing specifically on hospice, as its unique billing procedures and specialty certification more readily allow for the identification of hospice recipients and providers.

Second, there is a strong evidence base that demonstrates the benefits that hospice has on quality of life and cost of care at patients' end-of-life. The positive effect of hospice care on quality of life results from improved symptom control as well as increased patient and family satisfaction (Meier, 2011). Additionally, hospice use is associated with higher concordance between patient's stated end-of-life care preferences and actual end-of-life care received (Hughes & Smith, 2014; Kandelwal et al., 2017; Kumar et al., 2015; Meier, 2011) Studies of hospice care

consistently demonstrate reduced end-of-life costs, which arise primarily through: (1) avoiding emergency room visits and hospitalizations at the end-of-life, and (2) providing care in lower cost home- or community-based settings rather than higher-cost hospital settings (Morrison et al., 2008; Morrison et al., 2011; Research Data Assistance Center, 2016). Despite these reported benefits, hospice remains underused, with substantial geographic variation in use rates (MedPAC, 2019; Wang et al., 2015).

Third, estimates show that 80-85 percent of all hospice users are Medicare beneficiaries (NHPCO, 2018). Not only does the Medicare population represent most hospice users, but Medicare claims data include rich information about beneficiary demographics, their county of residence, the diagnoses warranting hospice care, the number of days receiving hospice, whether the beneficiary died while receiving hospice, and more (Research Data Assistance Center, 2016). Thus, most analyses of large-scale hospice trends examine Medicare claims data. Similarly, this analysis focuses on hospice care used by Medicare beneficiaries, since they represent the vast majority of hospice users, and, because of limited data on county-level hospice use from other payers.

Fourth, rates of hospice use are known to vary geographically, and the researchers could not find any studies that specifically examined rural Pennsylvania. Despite estimates that between 69 percent and 82 percent of all deaths from chronic illness are appropriate for hospice care (chronic illness is the cause of most deaths in the U.S, particularly in older age groups) (Murtagh et al., 2014), just under half of Medicare beneficiaries receive timely, appropriate hospice care (NHPCO, 2013; NHPCO, 2018). Examples of such chronic illnesses include respiratory diseases (e.g., chronic obstructive pulmonary disease), renal diseases (e.g., chronic kidney disease), circulatory or heart diseases (e.g., heart failure or stroke), cancers, and dementia (NHPCO,

2018). Additionally, in 2015, 27.9 percent of Medicare recipients that died while enrolled in hospice received seven or fewer days of hospice care prior to their death (NHPCO, 2018; MedPAC, 2019). While the optimal length of time on hospice is dependent on many factors, there is a perception among hospice providers that individuals are often referred to hospice too close to death, allowing them minimal time to fully meet the needs of patients and their families (e.g., develop a care plan that provides optimal symptom management, spiritual and psychosocial care, and respite care for family caregivers; Quill, 2007). While the vast majority of individuals enrolled in hospice care die while receiving hospice care, a minority do experience an improvement in health such that they no longer qualify for hospice or choose to disenroll in hospice prior to death (MedPAC, 2019; NHPCO, 2018).

Finally, a lack of provider availability and persistent educational, implementation, and policy barriers contribute to the overall underuse of hospice (Aldridge et al., 2016; Lupu, 2010; Rodriguez, Barnato, & Arnold, 2007; Quill & Abernethy, 2013). Examples of educational barriers include misperceptions of what hospice care is and/or an unwillingness to discuss uncomfortable end-of-life issues by both patients and their healthcare providers. An example of an implementation barrier is identifying the best time to refer patients to hospice care. Further, these barriers exist within a healthcare system that incentivizes costly, often futile interventional care at the end-of-life that is often misaligned with the patient's own stated values and preferences (Aldridge et al., 2016; Lupu, 2010; Rodriguez, Barnato, & Arnold, 2007; Quill & Abernethy, 2013).

Motivated by these and related issues, this study describes hospice availability and use across rural Pennsylvania and draws comparisons with urban areas. It also clarifies current challenges and potential opportunities to providing hospice care in rural Pennsylvania. However, such

challenges and opportunities are difficult to fully explore using solely Medicare claims data. Therefore, this research used a mixed-methods approach to analyze hospice availability and use in rural Pennsylvania by: (1) using a *quantitative* approach to estimate hospice utilization among different populations in Pennsylvania and how both availability and population characteristics may drive use for hospice care; and (2) incorporating a *qualitative* analysis of the perceived barriers and opportunities by hospice care providers and other stakeholders. These qualitative interviews gave stakeholders the opportunity to offer their perspectives from the field with the findings of the Medicare claims analyses.

GOALS AND OBJECTIVES

The overall goal of the research was to estimate current availability and use of hospice care in rural Pennsylvania and to estimate future hospice use. The goal was achieved by addressing the following four objectives.

1. Identify the type and coverage area of hospice providers in rural Pennsylvania. This research examined information on hospice providers serving rural Pennsylvania, including their location, characteristics (e.g., for-profit, nonprofit, hospital-based, home health agency-based, etc.), and the ZIP codes they serve. It also produced maps of the locations of hospices, each overlaid with an indicator of the county's rural (urban) status.

2. Examine availability of hospice providers and identify geographic areas in Pennsylvania with limited or no hospice providers. This study examined the availability of hospice providers and identified areas in rural Pennsylvania that currently have limited or no hospice providers. It described counties with limited hospice availability based on the analysis of data from Objective 1. It also identified the number of hospices serving a county, and the current

ratio of hospice providers to hospice users reported in Medicare's Market Saturation and Utilization files, and produced a map to display the variation in numbers of providers serving counties and ZIP codes.

3. Estimate current use of hospice services in rural Pennsylvania, differences in use rates by population characteristics, and project future hospice utilization by county. This research estimated the rates of hospice care use per Medicare decedent for each Pennsylvania county in 2006, 2011, and 2016. In addition, it provided the demographic characteristics of Pennsylvania's rural Medicare hospice users and the distribution of hospice utilization across demographic and chronic disease categories. The research then used current hospice use rates and projected future population changes to estimate future numbers of hospice users within each county in 2020, 2025, 2030, 2035, and 2040, and produced a table containing projections for each county. For comparison, the research provided similar statistical profiles for Pennsylvania's urban counties.

4. Identify challenges and opportunities to providing hospice care in rural Pennsylvania. To supplement the analyses of Medicare data, the researchers also conducted interviews with hospice care providers to better understand providers' perspectives about current and future challenges and opportunities to providing hospice care in rural Pennsylvania.

METHODOLOGY

Data: This study primarily analyzed data collected by the Centers for Medicare and Medicaid Services (CMS). The vast majority of hospice providers are CMS-certified to receive payment from Medicare or Medicaid; these data sources are therefore appropriate for providing

the hospice-specific information necessary for this research (Department of Health and Human Services, 2007). A list and brief description of the variables and data are included in Table 1.

Table 1. Data Sources

Dataset	Source	Availability	Year(s)	Variables/Description
Hospice Compare	CMS	Public	2017-2019	Provides information on hospice location and profit status.
Hospice ZIP Data	CMS	Public	2019	Lists all ZIP codes serviced by a hospice provider.
Provider of Service File	CMS	Public	2019	Hospice agency characteristics (e.g., freestanding, hospital-based, home health agency-based).
Market Saturation and Utilization	CMS	Public	2016	Number of hospice providers servicing a county, as well as number of hospice users per hospice provider per county. Estimated from ZIP codes of individuals using hospice collected in CMS claims data.
Hospice Public Use File	CMS	Public	2016	Primary diagnoses for hospice care claims submitted to CMS.
Hospice Limited Dataset	CMS	Restricted	2006, 2011, 2016	Beneficiary-level hospice claims data that include beneficiaries' state and county of residence, age, sex, race/ethnicity, and plan type (FFS or Medicare Advantage). Used to generate counts of hospice users per county.
Master Beneficiary Summary File	CMS	Restricted	2006, 2011, 2016	Beneficiary-level demographic information (e.g., state and county of residence, age, sex, race/ethnicity, and plan type (FFS or Medicare Advantage). Used to identify/count decedents; counts of decedents were then used to calculate rate of hospice use (count of hospice users/count of all decedents = hospice use rate)
PA County-Level Population Projections	Center for Rural PA	Public	Future Projections	Estimates of counts of county-level populations for years 2020, 2025, 2030, 2035, 2040 (including total population, by sex, and 5-year age group)

Notes: CMS = Centers for Medicare and Medicaid; PA = Pennsylvania; DOH = Department of Health; FFS = Fee-for-service

The researchers used five publicly available files to obtain hospice-specific information. The first, 2017-2019 Hospice Compare, provides the name, address, and hospice profit status (e.g., for-profit, nonprofit, or other) for all CMS-certified hospices (CMS, 2019a). The second, 2019 Hospice ZIP Data, lists all ZIP codes served by each CMS-certified hospice provider using a combination of hospice-reported ZIP codes served and ZIP codes listed on claims data (CMS, 2019b). The third, the 2019 Provider of Services file, reports hospice characteristics of interest (e.g., free-standing hospice versus home health agency-based hospice; CMS 2019c). Fourth, the 2016 Market Saturation and Utilization datasets aggregates ZIP code level data to calculate the county-level number of hospice providers as well as the number of hospice users per hospice provider (CMS, 2019d). Fifth, the 2016 Hospice Public Use File reports the primary diagnoses for hospice care (CMS, 2019e).

This study also drew heavily from two restricted CMS data sources. The first included the 2006, 2011, and 2016 Hospice Limited Data Sets (LDS; CMS, 2019f), which contain patient-level data on county of residence, age, sex, race/ethnicity, and the hospice diagnosis (i.e. terminal diagnosis) for all Medicare beneficiaries that enroll in hospice in a given year. The second restricted data sources were the 2006, 2011, and 2016 Master Beneficiary Summary (MBS) Files. The MBS files include demographic information for all Medicare beneficiaries in a given year (CMS, 2019f). The Hospice LDS and MBS Files required a data user agreement. The researchers worked with the appropriate information technology departments in both the College of Nursing and the Office of Research as well as the Penn State Institutional Review Board (IRB) to build the secure infrastructure required to analyze these data. Finally, this study used county-level population projections produced for the Center for Rural Pennsylvania (CRP) by the Pennsylvania State Data Center (CRP, 2013) to estimate future demand.

Measures: (1) Rurality: although multiple definitions exist (Economic Research Service, 2018), the research used the Center for Rural Pennsylvania's density-based definition of rural Pennsylvania counties. (2) Hospice utilization: the research calculated a county rate of hospice use as the number of Medicare hospice users divided by the total number of Medicare decedents in a given county and year. The research produced counts of hospice users – individuals with any hospice claim in a given year – to estimate future hospice utilization rates. (3) Provider density: the research used the CMS definition used for the Market Saturation and Utilization data, which is the average number of hospice providers in a county relative to the average number of Medicare beneficiaries in that county who used hospice care within a calendar year.

Analytic strategy: The analytic strategy for each of the four stated objectives is described below. Note that the researchers obtained IRB approval and CMS approval prior to obtaining data or beginning the analyses.

1. Identify the type and coverage area of hospice providers in rural Pennsylvania. Using data from CMS' Hospice Compare, Hospice Zip Data, and Provider of Service Files, the researchers first compiled information on all CMS-certified hospices in Pennsylvania, including the hospice name, address, facility characteristics (e.g., for-profit, nonprofit, other), county location, and service area. These data were used to create a state-level database, separated by rural and urban county status. Next, using the Market Saturation and Utilization dataset, the researchers created two maps that illustrate: (i) the number of hospice providers serving each county and (ii) the ratio of hospice providers to Medicare hospice users in each county. Each map indicates each county's rural status.

2. Identify geographic areas in Pennsylvania with limited or no hospice providers. The researchers estimated areas that are currently underserved: first, by analyzing the Market

Saturation and Utilization file for 2016 to determine the number of hospice providers per county; then by categorizing counties into quartiles and identifying counties that were in lowest quartile of hospice providers available (defined as three or fewer hospice providers). Next, the researchers used the CMS Hospice Zip File to identify ZIP codes within counties with no or limited (i.e. only a single) hospice providers, and used this data to produce a map of ZIP code-level hospice availability that illustrates the varying number of hospice providers serving each ZIP code. Finally, the researchers used the CMS Market Saturation and Utilization File, which estimates the number of hospice providers per Medicare beneficiary receiving hospice care, to identify counties in the lowest quartile of hospice providers per number of beneficiaries using hospice care.

3. Estimate current use of hospice services in rural Pennsylvania, differences in use rates by population characteristics, and estimate (project) future hospice use by county. This research analyzed data from the 2006, 2011, and 2016 Hospice Limited Data Sets to estimate the percentages of hospice users in each county by 5-year age group, sex, race/ethnicity, and rural-urban residency to develop a statistical profile of Pennsylvania's rural Medicare hospice users. This same statistical profile was then generated for the most recently available year (2016) for both rural counties and urban counties to identify differences in hospice use within each of these groups. This study also analyzed the change in hospice use rates between 2006, 2011, and 2016 in rural Pennsylvania, and compared the changes to state-level and national-level changes.

To better understand which conditions may have driven hospice use, the researchers then analyzed the distribution of Pennsylvania's Medicare hospice users across different disease categories (primary diagnosis warranting hospice care) to determine the most and least common diagnoses requiring hospice care, and whether any differences exist between rural and urban hospice users. Using the International Statistical Classification of Diseases and Related Health

Problems (ICD-10) codes reported by Medicare, the researchers focused on the standardized subset of diagnosis classifications from the Agency for Healthcare Research and Quality most commonly seen in hospice: cancer, cardiovascular disease, dementia, and other (CMS, 2018).

In addition to estimating current use and factors driving current use, the researchers also provided estimated projections of future hospice use using current hospice use rates and projected changes in county-level demographic data by age group. First, they calculated the county-level hospice use rate, defined here as the number of hospice users divided by the total population for the following age groups: ages 65-69, ages 70-74, ages75-79, ages 80-84, and ages 85 or older. They included two versions of this estimate using: a) the mean hospice use rates for each county between 2006, 2011, and 2016; and b) the hospice use rate for 2016. While the latter captures the most recent hospice use data, fully accounting for statewide changes in demand for hospice care, one concern would be that it does not capture year-to-year fluctuations in the hospice rate. By averaging across 3 years of data, the former better accounts for the year-to-year differences in the hospice use rate. Then, the age-group- and county-specific hospice use rates were combined with projected age-group-specific population numbers for each county for 2020, 2025, 2030, 2035, and 2040 from the Center for Rural Pennsylvania (CRP, 2013). Finally, the researchers examined several alternative models that used regression analysis to estimate how lagged, or prior years', age group population numbers could predict future hospice use. However, given the limited years of data and variable secular trends across the state between 2006 and 2016, the researchers found the estimates to be relatively unstable. Therefore, they focused on the aforementioned approach to estimate projected hospice use for 2020, 2025, 2030, 2035, and 2040.

4. Identify challenges and opportunities to providing hospice care in rural Pennsylvania. To better understand and identify challenges and opportunities for providing hospice care in rural Pennsylvania, the research supplemented the quantitative findings with hospice care provider interviews. One of the innovative aspects of this study is the incorporation of the provider's perspective in delivering hospice care to rural Pennsylvania residents, and presenting these data alongside the *quantitative* findings from Objectives 1-3 to provide a more complete picture of hospice care delivery in rural Pennsylvania. The qualitative analysis proceeded as follows:

Setting: Prior to any interview data collection, IRB approval was obtained from Penn State University. The general approach to identifying potential interviewees was to leverage the researchers' existing collaborative relationships with hospice care providers in Pennsylvania through personal outreach about the study, as well as to use the listserv of the Pennsylvania Hospice and Palliative Care Network for participant recruitment. Providers identified as practicing in a rural county (as defined above by the Center for Rural Pennsylvania) or providing care for patients residing in a rural county were invited to participate via an email.

Data collection and management: Providers were invited to either (a) participate in a telephone or in-person interview, or (b) complete a secure, online questionnaire if they were unable to participate in the live interview. The rationale for conducting two types of interviews was to obtain as large a sample as possible within the limited timeframe of the study. The goal of data collection for any rigorous *qualitative* inquiry is data saturation; interviews were continued until data saturation (i.e. no new information) was reached (Braun & Clarke, 2006; Creswell & Poth, 2007). The researchers determined that data saturation had been reached when the same information was appearing in the participant transcripts and no new information was revealed. Through purposive sampling, the researchers ensured that different hospice types (e.g. profit and

nonprofit), different types of providers (e.g., physicians, nurses, administrators), and various regions of rural Pennsylvania were represented to capture a comprehensive, interdisciplinary perspective.

After informed consent was obtained, individual interviews using traditional *qualitative* techniques took place over the phone or in-person and were audio recorded and transcribed verbatim by a professional transcription service. The interview guide and protocol were developed based on the research team's respective areas of expertise and the existing literature in this area. The interviews consisted of open-ended questions designed to explore provider perspectives regarding delivery of hospice care, with a focus on barriers, opportunities, and future trends and potential barriers. The individual phone interviews averaged 30 minutes in length per participant, providing rich descriptions of hospice delivery in rural Pennsylvania. The online questionnaire mirrored the individual interview, and participants were able to type their responses into text boxes. Additionally, each participant completed a demographic form along with their interview. All demographic information was stored in REDCap (Research Electronic Data Capture), which is a secure, web-based application available for Penn State researchers to build and manage online databases and surveys. The use of RedCap and the data management plan followed the standards set by Penn State's IRB to ensure the protection of the participants' identity and data.

Qualitative data analysis: This study used thematic analysis as described by Braun and Clarke for the interview data.[37,38] This method of thematic analysis identified, analyzed, organized, and reported themes and patterns found in the data to provide a rich and detailed account of the information captured in the interviews. All potentially identifying information was removed from the transcribed interviews prior to analysis. The researchers first generated an

initial list of codes from the first set of three transcripts; each interview transcript was then read and independently coded by the researchers using this set of codes. The researchers then reviewed the entire dataset together to identify themes or patterns of meaning. After coding 26 interviews, they determined that data saturation had been reached.

RESULTS

Objective 1. *Identify Type and Coverage Area of Hospice Providers in Rural Pennsylvania.* Table 2 includes the total number of hospice providers in rural and urban counties, and Pennsylvania as a whole by profit status for 2017, 2018 and 2019. There was an overall decrease in the number of hospice providers from 2017 to 2019 in both rural and urban counties. In rural Pennsylvania, there was a 12.5 percent decrease in the number of nonprofit hospice providers, but a 4.0 percent increase in for-profit hospice providers. In contrast, urban counties experienced a larger decrease in the number of for-profit hospice providers (-10.1 percent) and an increase in nonprofit hospice providers (6.8 percent increase). A larger share of hospice providers in rural Pennsylvania counties are nonprofit (51.9 percent) compared with urban counties (37.0 percent).

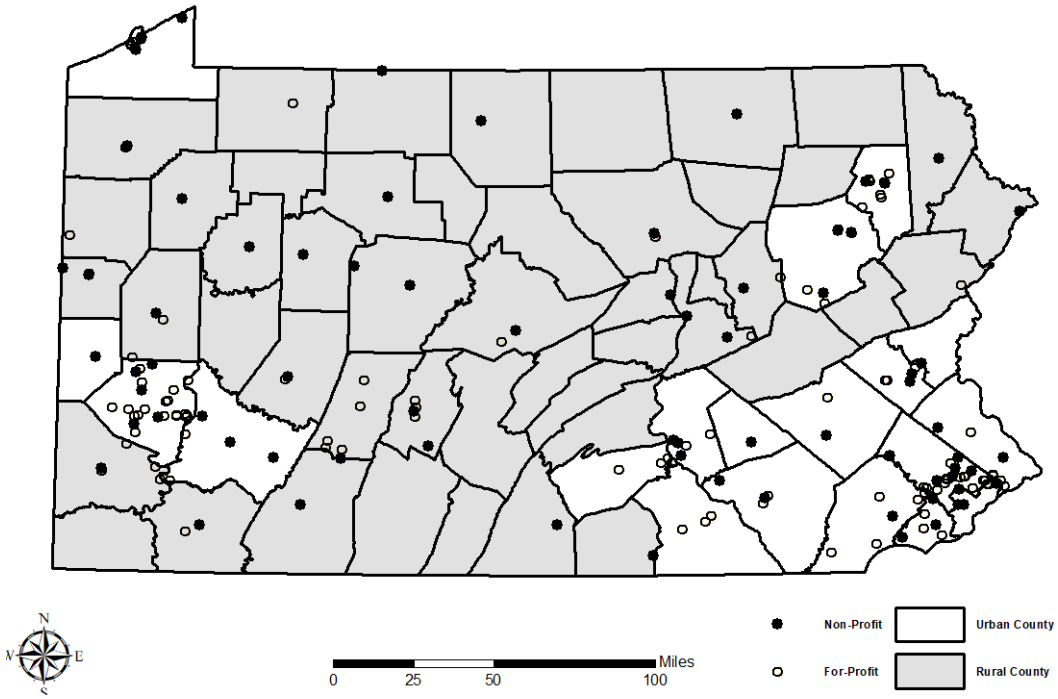
Table 2. Hospices in Pennsylvania's Rural and Urban Counties, 2017-2019

	2017		**2018**		**2019**		**Change, 2017-2019**
	N	%	n	%	n	%	% change
All PA	190	100	181	100	181	100	-4.7
Nonprofit	75	39.5	74	40.9	75	41.4	0
For-Profit	115	60.5	107	59.1	106	58.6	-7.8
Rural	56	29.5	54	29.8	54	29.8	-5.3
Nonprofit	31	55.4	31	57.4	28	51.9	-12.5
For-Profit	25	44.6	23	42.6	26	48.1	4.0
Urban	134	70.5	127	70.2	127	70.2	-4.5
Nonprofit	45	33.6	43	33.9	47	37.0	6.8
For-Profit	89	66.4	84	66.1	80	63.0	-10.1

Source: 2019 Hospice Compare

The distribution of hospices by profit status across Pennsylvania counties are displayed in Figure 1.

Figure 1. Pennsylvania Hospice Locations, by Profit Status



Source: 2019 Hospice Compare

Table 3 displays additional characteristics of hospice providers located in rural Pennsylvania counties. As shown in Table 3, the majority (76.9 percent) of for-profit hospices are free-standing facilities. Free-standing hospices are those hospice agencies not affiliated with a larger health care organization, such as a skilled nursing facility (SNF) or hospital (Chung, 2013). A hospice may be both free-standing *and* inpatient or provide care in the patient's home. An inpatient hospice is a facility that provides hospice care within a specialized hospice facility as opposed to a patient's home or SNF.

Only two (7.7 percent) of the for-profit hospice providers are inpatient hospice facilities. The remaining for-profit hospice providers provide services in the individual's place of residence

(e.g., home, nursing home, etc.); that is, if any hospice patient receiving care from these types of facilities requires an inpatient stay or respite care, the patient is transferred to other inpatient facilities, such as a nursing home or hospital. A larger share of nonprofit hospices are inpatient hospice facilities (14.3 percent). As with the for-profit hospice providers, the majority of nonprofit hospice providers provide care in the individual's place of residence and provide short-term respite care by transferring patients to non-hospice inpatient facilities, such as SNFs or hospitals.

Table 3. 2019 Rural Pennsylvania Hospice Facility Characteristics

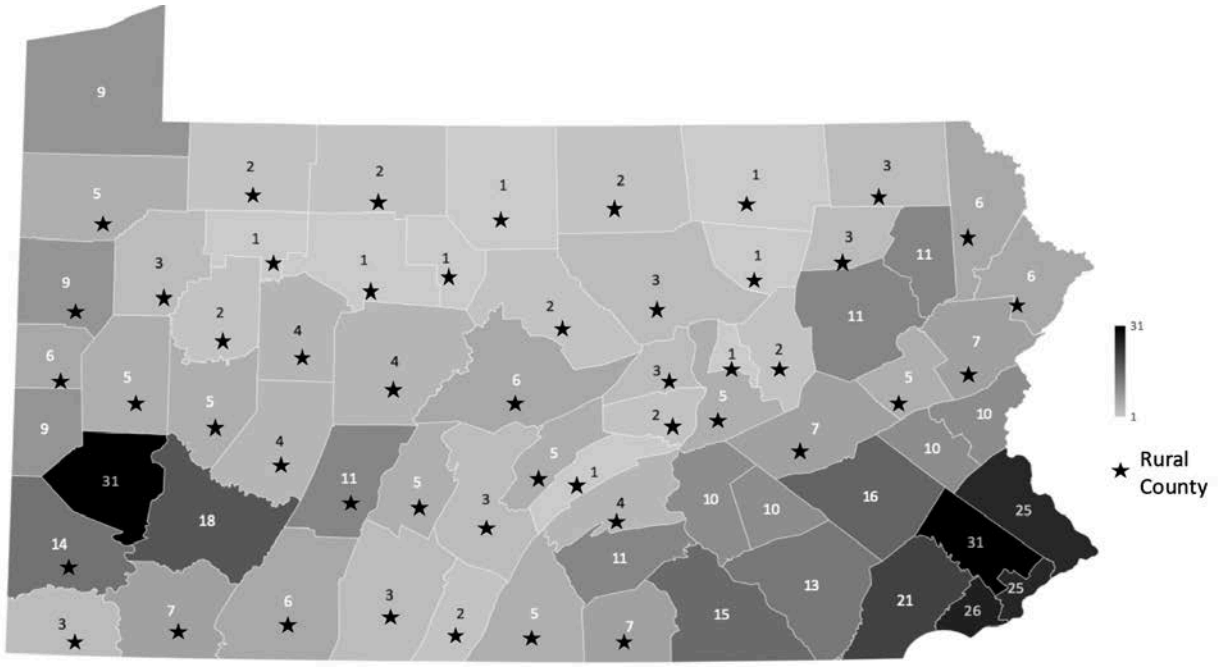
	n	%
Total	54	100
For-Profit	26	48.1
Free-Standing Hospice	20	76.9
Home Health Agency-Based	5	19.2
Hospital System-Based	1	3.8
Inpatient Hospice Facility	2	7.7
Nonprofit	28	51.9
Free-Standing Hospice	6	21.4
Home Health Agency-Based	14	50.0
Hospital-Based	8	28.6
Inpatient Hospice Facility	4	14.3

Source: 2019 Hospice Compare and Medicare Provider of Service Files

Objective 2*. Identify geographic areas in Pennsylvania with limited or no hospice providers*

Market saturation files. Figure 2 illustrates the number of hospice providers serving each county in 2016 based on estimates from the 2016 Market Saturation and Utilization file. A star indicates a rural county, and the darker gray to black shading indicates a greater number of hospice providers.

Figure 2. Number of Providers Per County, 2016



Note: Scale ranges from 1-31 providers, with darker grays indicating more providers and lighter grays indicating fewer providers. The actual number of providers within each county is also listed on the map itself. Source: 2016 Market Saturation File.

Among Pennsylvania's 48 rural counties, 24 were served by three or fewer hospice providers (Table 4). The analyses of the location of hospices in Objective 1 revealed that 15 counties did not have a hospice physically located in them; however, the analyses of the Market Saturation and Utilization data indicated that these counties are served by hospices in neighboring counties. This raises concern that there may be significant travel time for hospice staff, particularly if the hospice only provides care in the patient's home.

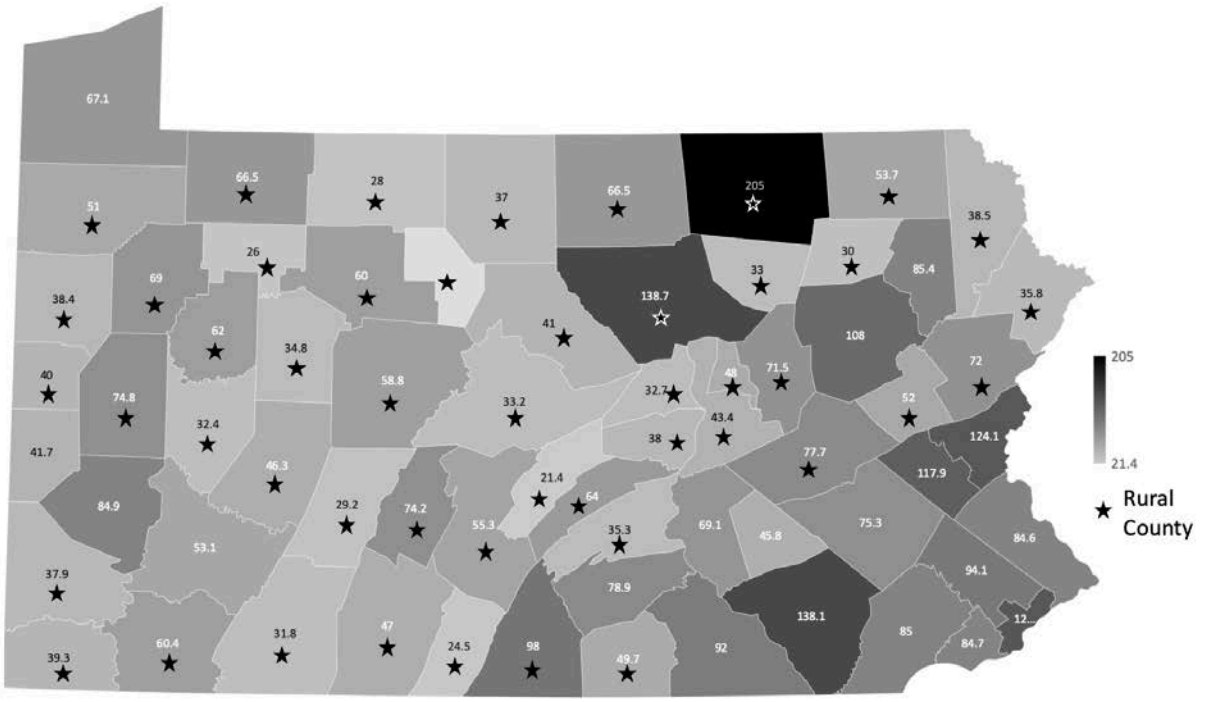
Table 4. Counties Served by Three or Fewer Hospice Providers

0 Hospice Providers	1 Hospice Provider	2 Hospice Providers	3 Hospice Providers
None	Bradford County	Clarion County	Bedford County
	Cameron County	Clinton County	Greene County
	Elk County	Columbia County	Huntingdon County
	Forest County	Fulton County	Lycoming County
	Juniata County	McKean County	Susquehanna County
	Montour County	Snyder County	Union County
	Potter County	Tioga County	Venango County
	Sullivan County	Warren County	Wyoming County

Source: 2016 Market Saturation File

Figure 3 illustrates the number of hospice users per hospice provider for each county as estimated by the CMS Market Saturation and Utilization file. Rural counties had, on average, fewer hospice users per hospice provider. However, the counties with the highest number of hospice users per provider were both rural (Bradford and Lycoming). The smaller number of users per provider in rural counties may partially reflect the lower overall hospice use rates among rural decedents (as shown in Objective 3) or relate to the size/capacity of the hospice provider.

Figure 3. Number of Hospice Users per Hospice Provider, 2016



Source: 2016 Market Saturation File

Objective 3*. Calculate current use of hospice services in rural Pennsylvania and estimate future use using population projections.* The researchers first calculated Pennsylvania-wide hospice use rates in 2006, 2011, 2016, and identified the characteristics of Medicare hospice users relative to overall Pennsylvania Medicare beneficiaries and decedents.

Table 5 displays the statistical profile of all Pennsylvania Medicare hospice users in 2006. In 2006, there were 2,260,333 Medicare beneficiaries in Pennsylvania, of which 122,740 (5.4 percent) died. Among 2006 Medicare decedents, 48,023 (39.1 percent) used hospice services prior to death. Table 5 also displays hospice use rates across different demographic groups. Female decedents used hospice at a higher rate (43.8 percent) than male decedents (33.4 percent). The highest rate of hospice use was among racial/ethnic groups that did not identify as white or black (41.5 percent); black decedents had the lowest rate of hospice use (35.0 percent).

Hospice use rates increased as decedent age increased, with the highest rate of hospice use among decedents age 85 years and over.

Table 5. Profile of Pennsylvania Medicare Hospice Users, 2006

	Beneficiaries n (%)	**Decedents n (%)**	**Hospice Use Among Decedents in Category n (%)**
Total	2,260,333	122,740 (5.4)	48,023 (39.1)
Sex			
Female	1,287,149 (56.9)	67,624 (43.8)	29,606 (43.8)
Male	973,184 (43.1)	55,116 (56.2)	18,417 (33.4)
Race/Ethnicity			
White	2,040,425 (90.1)	112,083 (91.3)	44,189 (39.4)
Black	174,733 (7.7)	9.088 (7.4)	3,185 (35.0)
Other	44,732 (2.0)	1,542 (1.3)	640 (41.5)
Age Group			
Under 65 years	426,770 (18.9)	9,633 (7.8)	2,136 (22.8)
65-69 years	463,375 (20.5)	9,727 (7.9)	3,031 (31.2)
70-74 years	409,420 (18.1)	13,389 (10.9)	4,705 (35.1)
75-79 years	390,439 (17.3)	20,060 (16.3)	7,523 (37.5)
80-84 years	306,481 (13.6)	25,423 (20.7)	10,301 (40.5)
85+ years	263,848 (11.7)	44,508 (36.3)	20,327 (45.7)
Medicare Plan			
Fee for service	1,521,697 (67.3)	87,849 (71.6)	33,980 (38.7)
Medicare Advantage	738,636 (32.7)	34,891 (28.4)	14,043 (40.2)

Source: 2006 Medicare Hospice and Denominator Limited Data Sets
Note: All numbers are rounded to nearest tenth and in some instances may not sum to 100.0%.

Table 6 displays the statistical profile of Pennsylvania Medicare hospice users in 2011. There were 2,440,049 Medicare beneficiaries – an increase of 7.9 percent from 2006. Of the 2011 Medicare beneficiaries, 126,277 (5.2 percent) died. Among 2011 Medicare decedents, 63,765 (50 percent) used hospice services prior to death. Table 6 also displays hospice use rates across different demographic groups. Female decedents continued to use hospice at a higher rate (56.7 percent) than male decedents (43.1 percent). White decedents used hospice at a higher rate (51.1 percent) than black decedents (43.9 percent) and beneficiaries of other races/ethnicities (48.4 percent); black decedents continued to use hospice at the lowest rate among these groups.

Hospice use again increased as age increased, with the highest rate of hospice use among decedents age 85 years or older.

Table 6. Profile of Pennsylvania Medicare Hospice Users, 2011

	Beneficiaries n (%)	**Decedents n (%)**	**Hospice Use Among Decedents in Category n (%)**
Total	2,440,049 (100)	126,277 (5.2)	63,765 (50.5)
Sex			
Female	1,365,408 (56.0)	68,917 (54.6)	39,067 (56.7)
Male	1,074,641 (44.0)	57,360 (45.4)	24,698 (43.1)
Race/Ethnicity			
White	2,174,095 (89.1)	114,972 (91.0)	58,724 (51.1)
Black	199,755 (8.2)	9,414 (7.5)	4,132 (43.9)
Other	65,494 (2.7)	1,854 (1.5)	897 (48.4)
Age Group			
Under 65 years	524,609 (21.5)	11,049 (8.7)	3,123 (28.3)
65-69 years	540,355 (22.1)	10,460 (8.3)	3,885 (37.1)
70-74 years	419,704 (17.2)	12,911 (10.2)	5,543 (42.9)
75-79 years	348,562 (14.3)	16,913 (13.4)	7,925 (46.9)
80-84 years	300,435 (12.3)	24,036 (19.0)	12,516 (52.1)
85+ years	306,384 (12.6)	50,908 (40.3)	30,773 (60.4)
Medicare Plan			
Fee for service	1,504,331 (61.7)	82,456 (65.3)	40,680 (49.3)
Medicare Advantage	935,718 (38.3)	43,821 (34.7)	23,085 (52.7)

Source: 2011 Medicare Hospice and Denominator Limited Data Sets
Note: All numbers are rounded to nearest tenth and in some instances may not sum to 100.0%.

Table 7 displays the statistical profile of Pennsylvania Medicare hospice users in 2016. There were 2,702,988 Medicare beneficiaries in Pennsylvania – an increase of 10.1 percent from 2011. Of these beneficiaries, 133,591 (4.9 percent) died in 2016. Among 2016 Medicare decedents, 69,307 (51.2 percent) used hospice services prior to death. While the rate of hospice use among males increased by 4.9 percent compared to 1.9 percent for females, female decedents continued to use hospice at a higher rate than male decedents. Hospice use among white and black decedents increased, with white decedents continuing to use hospice at rates higher than black and other racial/ethnic decedents. Hospice use again increased as decedent age increased, with the highest rate of hospice use among decedents age 85 years and older.

Table 7. Profile of Pennsylvania Medicare Hospice Users, 2016

	Beneficiaries n (%)	Decedents n (%)	Hospice Use Among Decedents in Category n (%)
Total	2,702,988 (100)	133,591 (4.9)	69,307 (51.9)
Sex			
Female	1,489,378 (55.1)	71,317 (53.4)	41,186 (57.8)
Male	1,213,610 (44.9)	62,274 (46.6)	28,121 (45.2)
Race/Ethnicity			
White	2,357,190 (87.2)	120,346 (90.1)	63,305 (52.6)
Black	232,342 (8.6)	10,520 (7.9)	4,746 (45.1)
Other	112,652 (4.2)	2,682 (2.0)	1,229 (45.8)
Age Group			
Under 65 years	568,001 (21.0)	12,111 (9.1)	3,354 (27.7)
65-69 years	693,449 (25.7)	13,274 (9.9)	5,000 (37.7)
70-74 years	489,824 (18.1)	14,581 (10.9)	6,260 (42.9)
75-79 years	359,655 (13.3)	17,238 (12.9)	8,381 (48.6)
80-84 years	270,929 (10.0)	21,420 (16.0)	11,606 (54.2)
85+ years	321,130 (11.9)	54,967 (17.1)	34,706 (63.1)
Medicare Plan			
Fee for service	1,607,249 (59.5)	78,901 (59.1)	39.394 (49.9)
Medicare Advantage	1,095,739 (40.5)	54,690 (40.9)	29,913 (54.7)

Source: 2016 Medicare Hospice and Denominator Limited Data Sets
Note: All numbers are rounded to nearest tenth and in some instances may not sum to 100.0%.

Pennsylvania hospice use rates compared to national hospice use rates. Table 8 compares hospice use rates between Pennsylvania and the entire U.S. in 2006, 2011, and 2016 by demographic group. Across all 3 years of data, Pennsylvania had slightly higher rates of hospice use among all demographic groups, with a few exceptions: decedents that were (1) under age 65 in 2006 and 2016; (2) age 65 to 74 in 2006 and 2016; and (3) age 75-84 in 2016 used hospice at slightly lower rates in Pennsylvania compared to nationwide rates.

Table 8. Hospice Use Rates (%) in Pennsylvania and Nationally, 2006-2016

	2006 PA	2006 US	2011 PA	2011 US	2016 PA	2016 US	PA % change, 2006-2016	US % change, 2006-2016
All Beneficiaries	39.1	37.0	50.5	45.2	51.9	49.7	32.7	34.3
Sex								
Female	43.8	39.4	56.7	48.6	57.8	53.7	32.0	36.3
Male	33.4	34.1	43.1	41.3	45.2	45.4	35.3	33.1
Race/Ethnicity								
White	39.4	38.5	51.1	47.0	52.6	51.8	33.5	34.5
Black	35.0	28.2	43.9	35.4	45.1	38.8	28.9	37.6
Other	41.5	26.7	48.4	33.6	45.8	38.2	10.4	43.1
Age Group								
<65 years	22.8	23.7	28.3	27.8	27.7	30.1	21.5	27.0
65-74 years	33.2	34.2	40.0	39.3	37.7	41.4	13.6	21.0
75-84 years	39.0	38.1	49.5	46.3	42.9	50.7	10.0	33.1
85+ years	45.7	41.0	60.4	52.0	63.1	59.1	38.1	44.1
Medicare Plan								
FFS	38.7	36.2	49.3	44.2	49.9	48.7	28.9	34.5
MA	40.2	41.3	52.7	48.9	54.7	51.9	36.1	25.7

Source: 2006, 2011, & 2016 Medicare Hospice and Denominator Limited Data Sets (PA Rates); 2011, 2013, & 2018 MedPAC Report (USA Rates)
Note: All numbers are rounded to nearest tenth and in some instances may not sum to 100.0%. FFS = Fee-for-service, MA = Medicare Advantage, Dual Eligibility = also eligible for Medicaid.

Hospice use in rural Pennsylvania. Table 9 compares hospice use rates between Pennsylvania rural and urban counties by demographic group using the 2006, 2011, and 2016 Hospice Limited Data Sets, and the 2006, 2011, and 2016 Master Beneficiary Summary File datasets. The analyses show that, overall, hospice use rates were lower among all demographic groups in rural counties compared to the same demographic groups in urban counties. However, for both rural and urban counties, female (vs. male), white (vs. non-white), age 85 years or older (vs. under age 85), and Medicare Advantage (vs. Medicare fee-for-service) had higher rates of hospice use. In both rural and urban counties, hospice use rates increased monotonically as beneficiary age increased.

Table 9. Comparison of Pennsylvania Rural-Urban Hospice Use Rates Among Demographic Groups; 2006, 2011, 2016

	2006		2011		2016	
	Rural	Urban	Rural	Urban	Rural	Urban
Total	32.9	41.6	47.0	51.7	46.2	54.0
Sex						
Female	36.4	46.6	52.4	58.0	51.2	60.1
Male	28.8	35.3	40.9	43.8	40.7	46.9
Race/Ethnicity						
White	32.9	42.3	47.1	52.7	46.4	55.3
Black	23.7	35.5	41.9	43.7	39.5	45.3
Other	48.1	40.2	48.4	48.0	43.4	45.7
Age Group						
Under 65 years	21.9	22.3	28.6	28.1	26.0	28.4
65-69 years	28.1	32.5	37.4	37.0	35.0	38.9
70-74 years	32.2	36.4	40.6	44.0	40.4	44.1
75-79 years	32.9	39.6	45.9	47.3	44.1	50.1
80-84 years	34.2	43.1	49.2	53.2	49.2	56.3
85+ years	36.1	50.0	54.7	62.0	55.1	65.6
Medicare Plan						
Fee for service	31.7	41.8	44.5	51.4	43.5	52.7
Medicare Advantage	36.4	41.0	51.8	52.1	50.2	55.8

Source: 2006, 2011, 2016 Hospice Limited Data Set and 2006, 2011, 2016 Master Beneficiary Summary File

County-level hospice use among all Medicare decedents. While Table 9 displays the mean hospice use rates for rural counties and urban counties, Table 10 presents individual county hospice use rates, stratified by number of providers. In 2016, 100 percent of counties with three or fewer hospice providers were rural. With the exception of seven counties (Blair, Centre, Clearfield, Jefferson, Mercer, Mifflin, and Pike), all rural counties with four or more hospice providers bordered non-rural counties. That is, of the 24 rural counties with four or more hospice providers, 71 percent (17/24) bordered non-rural counties (see Table 10). In counties served by one hospice provider in the most recent year of data available (2016), hospice use rate among decedents ranged from 20.7 percent to 54.4 percent with an average rate of 35.7 percent. In counties served by two hospice providers in 2016, hospice use rate among decedents ranged

from 15.8 percent to 45.2 percent, with an average rate of 36.0 percent. In counties served by three hospice providers, hospice use rate among decedents ranged from 40.2 percent to 53.9 percent, with an average rate of 48.2 percent. In counties served by four or more hospices in 2016, hospice use rates among decedents ranged from 37.3 percent to 61.4 percent with an average rate of 49.7 percent. Overall, there was an increase in county-level hospice use rates between 2006 and 2016, with the exception of Montour and Lackawanna counties. County-level hospice use rates ranged from 11 percent to 60 percent among all Medicare beneficiaries in 2006, and 16 percent to 64 percent in 2016 (Table 10). The five counties with the highest percent increase in hospice use rates among decedents between 2006 and 2016 were Fulton County (89.3 percent increase), Juniata County (90.5 percent increase), Mercer County (96.6 percent increase), Sullivan County (113 percent increase), and Venango County (88.9 percent increase).

Table 10. Pennsylvania County-Level Hospice Use Rates, 2006, 2011, 2016 and Percent Change

County	2006	2011	2016	% change 2006-2016
Counties Serviced by 1 Hospice Provider in 2016				
BRADFORD (R)	30.4%	36.7%	39.2%	28.9%
CAMERON (R)	12.8%	22.6%	20.7%	61.7%
ELK (R)	14.1%	26.7%	20.7%	46.8%
FOREST (R)	31.1%	43.9%	52.8%	69.8%
JUNIATA (R)	20.1%	41.5%	38.3%	90.5%
MONTOUR (R)	38.3%	33.7%	35.7%	-6.8%
POTTER (R)	16.1%	28.6%	24.0%	49.1%
SULLIVAN (R)	25.5%	43.9%	54.4%	113.3%
Counties Serviced by 2 Hospice Providers in 2016				
CLARION (R)	33.2%	39.9%	37.6%	13.3%
CLINTON (R)	29.3%	43.3%	33.3%	13.7%
COLUMBIA (R)	42.2%	50.5%	45.2%	7.1%
FULTON (R)	21.4%	40.9%	40.5%	89.3%
MCKEAN (R)	11.2%	19.5%	15.8%	41.1%
SNYDER (R)	27.8%	32.9%	40.9%	47.1%
TIOGA (R)	26.0%	34.9%	35.7%	37.3%
WARREN (R)	32.5%	50.4%	39.0%	20.0%

Counties Serviced by 3 Hospice Providers in 2016				
BEDFORD (R)	39.4%	63.0%	48.4%	22.8%
GREENE (R)	37.3%	63.1%	53.9%	44.5%
HUNTINGDON (R)	41.8%	52.0%	49.1%	17.5%
LYCOMING (R)	37.5%	49.5%	49.4%	31.7%
SUSQUEHANNA (R)	28.8%	44.8%	43.9%	52.4%
UNION (R)	22.1%	38.8%	40.2%	81.9%
VENANGO (R)	27.9%	34.5%	52.7%	88.9%
WYOMING (R)	42.5%	48.4%	47.7%	12.2%
Counties Serviced by 4 or More Hospice Providers in 2016				
ADAMS (R)	40.5%	51.3%	44.9%	10.9%
ALLEGHENY	43.1%	55.2%	55.6%	29.0%
ARMSTRONG (R)	31.0%	46.0%	53.9%	73.9%
BEAVER	36.5%	45.2%	53.9%	47.7%
BERKS	33.7%	44.3%	49.4%	46.6%
BLAIR (R)	44.9%	67.2%	47.0%	4.7%
BUCKS	45.6%	56.4%	56.5%	23.9%
BUTLER (R)	40.5%	54.9%	54.2%	33.8%
CAMBRIA (R)	40.9%	63.1%	49.8%	21.8%
CARBON (R)	28.3%	42.7%	42.7%	50.9%
CENTRE (R)	20.9%	46.4%	39.4%	88.5%
CHESTER	46.5%	55.9%	64.8%	39.4%
CLEARFIELD (R)	38.1%	44.1%	41.0%	7.6%
CRAWFORD (R)	24.3%	41.3%	43.8%	80.2%
CUMBERLAND	36.8%	51.8%	57.8%	57.1%
DAUPHIN	37.3%	46.4%	53.5%	43.4%
DELAWARE	39.3%	53.9%	60.8%	54.7%
ERIE	28.6%	42.5%	39.0%	36.4%
FAYETTE (R)	39.5%	59.5%	61.2%	54.9%
FRANKLIN (R)	33.9%	43.5%	42.3%	24.8%
INDIANA (R)	33.4%	49.8%	50.6%	51.5%
JEFFERSON (R)	24.9%	38.6%	39.0%	56.6%
LACKAWANNA	51.7%	56.8%	51.0%	-1.4%
LANCASTER	56.0%	58.9%	56.3%	0.5%
LAWRENCE (R)	33.8%	42.5%	49.1%	45.3%
LEBANON	40.5%	45.9%	52.2%	28.9%
LEHIGH	43.1%	50.2%	52.9%	22.7%
LUZERNE	37.2%	44.7%	42.3%	13.7%
MERCER (R)	23.3%	37.0%	45.8%	96.6%
MIFFLIN (R)	33.8%	56.5%	39.2%	16.0%
MONROE (R)	33.0%	48.4%	48.6%	47.3%
MONTGOMERY	45.2%	56.6%	58.6%	29.6%
NORTHAMPTON	37.5%	50.9%	55.4%	47.7%
NORTHUMBERLAND (R)	23.0%	28.6%	33.3%	44.8%
PERRY (R)	32.8%	46.5%	51.8%	57.9%

PHILADELPHIA	40.3%	47.2%	48.5%	20.3%
PIKE (R)	34.4%	42.9%	50.5%	46.8%
SCHUYLKILL (R)	24.5%	30.8%	37.3%	52.2%
SOMERSET (R)	28.5%	53.3%	49.6%	74.0%
WASHINGTON (R)	40.3%	58.3%	60.5%	50.1%
WAYNE (R)	39.3%	46.5%	45.1%	14.8%
WESTMORELAND	37.8%	56.6%	61.4%	62.4%
YORK	38.7%	43.2%	47.8%	23.5%

(R) indicates county is rural

Primary hospice diagnoses. Table 11 displays the most common primary diagnoses for hospice care by rurality in 2016. In both rural and urban counties, cancer and heart disease are the most prevalent primary diagnoses among Medicare beneficiaries receiving hospice care. In general, there are similar percentages of primary diagnoses in rural areas and urban areas, although cancer, heart disease, and missing diagnoses make up a relatively greater fraction of primary diagnoses in rural areas.

Table 11. Distribution of Primary Diagnosis Categories, 2016

	Rural	Urban
Primary Diagnosis		
Cancer	29.8%	26.8%
Dementia	14.3%	17.0%
Stroke	4.9%	7.7%
Circulatory/Heart Disease	22.5%	20.8%
Respiratory Disease	10.0%	10.2%
Other	14%	15.6%
Missing	4.5%	2.0%

Source: 2016 Hospice Public Use File
Note: Due to rounding, values may not sum to 100.0

Projected number of hospice users. Table 12 displays the projected number of hospice users based on each county's average hospice use rate from 2006, 2011, and 2016, combined with projections of age group-specific population numbers for 2020, 2025, 2030, 2035, and 2040.

Table 12. Projected Hospice Users Per Pennsylvania County based on Estimated Population Size by Age and Year (based on county average of 2006, 2011, and 2016 hospice utilization rates)

RURAL COUNTIES					
County	**2020**	**2025**	**2030**	**2035**	**2040**
ADAMS	461	529	613	699	767
ARMSTRONG	461	507	572	648	710
BEDFORD	323	361	401	438	475
BLAIR	868	967	1,096	1,223	1,313
BRADFORD	299	343	394	438	470
BUTLER	1,070	1,228	1,441	1,678	1,876
CAMBRIA	1,057	1,140	1,258	1,384	1,474
CAMERON	14	16	17	17	17
CARBON	347	387	438	488	529
CENTRE	411	473	554	642	718
CLARION	181	208	238	266	290
CLEARFIELD	442	494	553	614	661
CLINTON	155	175	195	216	230
COLUMBIA	402	441	492	547	586
CRAWFORD	424	479	547	609	650
ELK	84	92	100	110	118
FAYETTE	1,050	1,172	1,334	1,501	1,627
FOREST	47	54	59	59	58
FRANKLIN	661	737	834	930	1,017
FULTON	55	63	70	76	83
GREENE	263	298	342	385	417
HUNTINGDON	264	299	339	376	401
INDIANA	473	532	604	678	734
JEFFERSON	205	224	248	274	296
JUNIATA	76	87	98	110	120
LAWRENCE	552	591	647	716	771
LEBANON	787	872	991	1,109	1,203
LEHIGH	664	737	832	926	998
LYCOMING	89	101	113	122	127
MCKEAN	531	574	631	689	729
MERCER	250	270	291	309	323
MIFFLIN	749	906	1,097	1,293	1,460
MONROE	264	299	339	376	401
MONTOUR	97	103	112	121	126
NORTHUMBERLAND	377	413	454	492	519
PERRY	223	265	312	354	380
PIKE	211	247	289	328	359
POTTER	60	68	75	80	81
SCHUYLKILL	666	721	798	884	948

SNYDER	128	144	163	180	194
SOMERSET	448	490	543	599	639
SULLIVAN	45	51	56	61	61
SUSQUEHANNA	207	238	272	299	316
TIOGA	164	187	211	230	244
UNION	150	165	184	201	215
VENANGO	289	328	372	412	441
WARREN	223	252	288	321	342
WASHINGTON	1,543	1,721	1,952	2,208	2,400
WAYNE	397	455	522	572	597
WYOMING	167	194	228	257	279
URBAN COUNTIES					
County	**2020**	**2025**	**2030**	**2035**	**2040**
ALLEGHENY	7,557	8,202	9,207	10,425	11,448
BEAVER	1,046	1,130	1,252	1,395	1,511
BERKS	1,829	2,036	2,337	2,687	2,975
BUCKS	3,603	4,160	4,962	5,893	6,758
CHESTER	2,428	2,833	3,407	4,057	4,664
CUMBERLAND	1,376	1,552	1,792	2,044	2,236
DAUPHIN	1,280	1,477	1,732	2,019	2,251
DELAWARE	3,068	3,406	3,944	4,577	5,121
ERIE	1,160	1,310	1,497	1,687	1,839
LACKAWANNA	1,549	1,681	1,875	2,092	2,255
LANCASTER	3,112	3,444	3,922	4,460	4,930
LEBANON	1,792	1,994	2,301	2,670	3,001
LEHIGH	1,813	1,963	2,188	2,434	2,615
LUZERNE	4,753	5,264	6,101	7,131	8,114
MONTGOMERY	1,586	1,763	2,034	2,336	2,584
NORTHAMPTON	6,280	7,144	8,232	9,416	10,461
PHILADELPHIA	2,596	2,836	3,183	3,588	3,892
WESTMORELAND	2,009	2,318	2,727	3,173	3,554
YORK	7,557	8,202	9,207	10,425	11,448

Calculated using Center for Rural Pennsylvania Population Projections

Table 13 presents numbers similar to Table 12, with the exception that Table 13 is based on only county-level 2016 hospice use rates, with age group-specific population projections (vs. taking the average hospice use rates for 2006, 2011, and 2016 as in Table 12). Rates in Tables 12 and 13 are qualitatively similar.

Table 13. Projected Hospice Users Per Pennsylvania County based on Estimated Population Size by Age and Year (based on 2016 county hospice utilization rates)

RURAL COUNTIES					
County	**2020**	**2025**	**2030**	**2035**	**2040**
ADAMS	429	492	570	649	712
ARMSTRONG	553	608	684	775	852
BEDFORD	326	365	405	442	480
BLAIR	829	921	1,042	1,166	1,255
BRADFORD	321	369	424	476	514
BUTLER	1,134	1,303	1,526	1,779	1,988
CAMBRIA	1,060	1,140	1,254	1,380	1,473
CAMERON	12	14	15	16	16
CARBON	373	416	469	522	566
CENTRE	415	476	558	649	727
CLARION	194	222	254	285	311
CLEARFIELD	434	485	544	604	650
CLINTON	141	160	181	201	216
COLUMBIA	368	405	449	498	531
CRAWFORD	522	587	672	755	814
ELK	85	92	101	111	120
FAYETTE	1,222	1,365	1,552	1,745	1,888
FOREST	47	55	62	64	64
FRANKLIN	684	761	863	967	1,062
FULTON	72	82	92	101	111
GREENE	276	311	358	407	443
HUNTINGDON	262	296	337	375	401
INDIANA	547	611	690	775	849
JEFFERSON	242	265	290	317	340
JUNIATA	83	93	105	120	132
LAWRENCE	653	695	759	844	916
LYCOMING	720	802	911	1,016	1,094
MCKEAN	82	94	105	113	117
MERCER	695	750	825	903	960
MIFFLIN	214	231	250	265	276
MONROE	797	965	1,170	1,390	1,584
MONTOUR	74	80	87	93	96
NORTHUMBERLAND	436	476	524	568	598
PERRY	265	315	374	429	465
PIKE	217	257	303	346	383
POTTER	65	75	85	93	96
SCHUYLKILL	798	865	955	1,060	1,136
SNYDER	144	162	183	202	219
SOMERSET	512	560	619	683	729
SULLIVAN	52	59	63	68	66

SUSQUEHANNA	229	265	305	337	364
TIOGA	180	206	233	257	276
UNION	158	174	193	212	227
VENANGO	364	414	471	521	557
WARREN	194	219	251	277	295
WASHINGTON	1,742	1,941	2,200	2,493	2,716
WAYNE	452	521	596	653	681
WYOMING	169	197	230	257	278
URBAN COUNTIES					
County	**2020**	**2025**	**2030**	**2035**	**2040**
ALLEGHENY	7,931	8,591	9,643	10,945	12,056
BEAVER	1,227	1,325	1,467	1,633	1,769
BERKS	2,027	2,265	2,603	2,987	3,301
BUCKS	3,572	4,137	4,926	5,821	6,633
CHESTER	2,573	3,000	3,610	4,308	4,963
CUMBERLAND	1,513	1,706	1,971	2,249	2,460
DAUPHIN	1,451	1,675	1,967	2,305	2,582
DELAWARE	3,521	3,906	4,526	5,264	5,898
ERIE	1,203	1,356	1,544	1,737	1,898
LACKAWANNA	1,405	1,526	1,704	1,902	2,049
LANCASTER	2,865	3,186	3,628	4,104	4,505
LEBANON	803	896	1,019	1,134	1,221
LEHIGH	1,890	2,098	2,420	2,811	3,166
LUZERNE	1,786	1,939	2,161	2,397	2,569
MONTGOMERY	4,691	5,209	6,043	7,058	8,022
NORTHAMPTON	1,747	1,943	2,241	2,576	2,850
PHILADELPHIA	6,680	7,585	8,733	10,008	11,144
WESTMORELAND	3,020	3,301	3,710	4,186	4,546
YORK	2,150	2,484	2,918	3,384	3,776

Calculated using Center for Rural Pennsylvania Population Projections

Objective 4. *Identify challenges and opportunities to providing hospice care in rural Pennsylvania*

A total of 26 rural hospice providers participated. Eight participants completed an individual interview and 18 participants completed the online survey. Demographics of the sample are in Table 14.

Table 14. Demographics of Interview Participants

Age	**n=26**
Mean 45.3	Range 24-62 years of age
Gender	
Male	n=2
Female	n=24
Profession	**n=24**
MD/DO*	n=9
APRN/PA**	n=5
RN***	n=10
Hospice Palliative Medicine Fellowship or Certification	
MD/DO	Yes n=9 No n=0
APRN/PA	Yes n=3 No n=2
RN	Yes n=6 No n=4

* MD/DO: Medical Doctor
**APRN/ PA: Advanced Practice Registered Nurse; Physician Assistant
*** RN: Registered Nurse

All participants who completed informed consent finished data collection. The targeted proposed sample was 50 but data saturation was reached with 26 participants. Data saturation was determined during the analysis process. All the participants shared rich and detailed descriptions of providing hospice or palliative care to residents of rural Pennsylvania. The major themes identified were: *barriers to hospice delivery, facilitators to hospice delivery*, and a*reas for improvement.*

Barriers to hospice delivery. The most prevalent thematic area discussed by providers was the barriers to hospice delivery. The thematic area of *barriers* was further divided into three main subcategories of: *geographic barriers, staffing, hospice delivery.*

Geographic barriers. Many participants discussed at length the challenges that geography presents in providing hospice services. In some cases, providers covered up to a two-hour distance (one way) from their home base. In addition to the distance traveled, the remoteness of areas posed additional challenges, with many practitioners describing being on unpaved roads and not being able to find a location when GPS services did not work. Providers also described

how the difficulty of finding a location added additional time to an already long distance. The following quotes exemplify the challenges for hospice providers delivering home-based hospice care in rural Pennsylvania.

> *Perry County is probably the most rural that I've been. It takes some time for us to even find their homes. Just logistically speaking, I've gotten lost countless times trying to find a home that's in the middle of a very, very rural area where there's not a lot of GPS coverage.*

> *So, our organization reimburses for mileage and that is basically every patient visit. What we're finding organizationally, because we're taking patients in a very large catchment area and that includes a very significant portion of rural patients that our mileage reimbursement is going kind of sky high.*

The remoteness of many locations provided challenges related to cell service in addition to lack of GPS. The lack of cell service also impacted the practitioners' ability to communicate with other providers for needed services, as well as the ability to access the patient's electronic health record (EHR) in real-time for pertinent patient information, such as vital signs, lab values, etc. The lack of real-time access to the EHR was also identified as a barrier to documentation. Many participants described how the lack of cell service then required them to document in the electronic health record when they returned home or to the office, delaying information exchange with other providers and adding additional work hours to an already busy workday. The challenges of lack of cell service are highlighted by the following quote:

> *I have had numerous occasions where the nurse is on her cell phone trying to call me and the reception is totally poor and families don't have landlines. And that's a huge problem because then I can't communicate with my nurse about the issues that they're seeing in the patient's home. It just becomes a logistical nightmare about, okay, can you drive like 15 minutes away from the house to give me an update and then drive back? It's just a nightmare.*

Staffing. Participants detailed the impact of poor staffing and hospice delivery to residents in rural Pennsylvania. The main thematic areas described by participants were focused on staffing shortages, staff turnover, and burnout, and are exemplified by the following quotes.

The nighttime nursing staff we would need, I would honestly like to double. I think we have usually two nurses working at night, but that's covering a tremendously large territory. Sometimes we have a nurse on phone triage, but if we could have a nurse in each geographic area that we have patients that would be hugely beneficial because you have to cover sometimes from point-to-point, patient-to-patient's home that is two hours, two and a half hours. It's impossible to do that and provide urgent hospice care for patients who are in acute crisis.

We've had a lot of turnover in our social work department. It becomes a very significant challenge because you're not able to meet the needs of patients and everyone's spread really thin. So, we sometimes will utilize agency nurses for evening shift, which I don't like to do because they're not continuous, they're there for a contracted period of time, a couple of weeks at a time. So, it's a very different situation when you're a provider dealing with a nurse who's newer compared to a nurse that's been there for years.

I'm concerned about workforce, not just physicians, but all around nurses, social workers, chaplains wanting to do this type of work because of the resilience concerns and also the financial feasibility of it. Hospice agencies are under more scrutiny from the Office of the Inspector General and they may not be able to maintain a hospice business plan in some of these rural areas because of the overhead. Right. And that is a, that is a concern.

Hospice delivery. Hospice delivery from the perspective of the rural provider was described as "challenging" by nearly all participants, and the challenges were many. They described having limited choices of hospice providers as a challenge for patients and their families seeking a particular type of hospice care (e.g., in a particular setting). The lack of coordinated interdisciplinary services in rural areas was another significant challenge, which required providers to "patch things together" to meet the needs of patients and their families. The lack of available inpatient hospice facilities resulted in patients not wanting or able to receive hospice care in their home being placed in an inpatient hospice facility that was a distance from their home, or patients were placed in acute inpatient settings, such as hospitals or nursing homes. The downstream implications of the lack of inpatient hospice facilities resulted in significant travel distances for families to be with patients at the end of life as well as patients perhaps dying in a facility that was not congruent with their end-of-life preferences or wishes.

Hospice as a service line in any setting is typically underused or initiated very late in the illness trajectory. This delay in services was amplified for patients in rural Pennsylvania. Service delays encompassed many of the issues previously described. The outcome that perhaps has the biggest implication for rural patients at the end of life was that, when services need to be implemented quickly because death was only a short period away (1-2 days), providers really struggled logistically to get the staff and services to those rural patients.

> *It becomes quite difficult to have coordinated care with their [care team ordering hospice]. It's become quite a challenge at times to have their symptoms managed well because of a couple of reasons. Number one, if I have to start infusions on them, it takes a lot longer to get that medication delivered.*
>
> *In terms of our organization, we don't have a general inpatient hospice building or unit. If we did, this would be a very different conversation. But, we utilize the hospitals that are in our catchment area for general inpatient hospice care. There are times where patients are, they can't get inpatient hospice with us because the hospice, the hospital rather they go to, to receive general inpatient care we don't contract with just because it's so far away from us. But I would say if a person needs general inpatient hospice care, we tend to have them go to a hospital where we have contracts with. But it might be an hour away from their home.*
>
> *Unfortunately, there are times where patient care, just given how difficult it is to provide care for them based on where they live, they may be more apt to utilize the ER just because it's faster.*
>
> *Sometimes it's a lot more difficult to find a pharmacy that carries [hospice] medications and it's not just opiates. Other common medications that I find very readily in a local pharmacy in the city, those are really difficult to find locally for families that are living rurally. So we have a courier service that will deliver medications to patients in their homes if they're not able to go out of the home. But the courier will then have to go an hour out of the way of the patient's home to go to that pharmacy and then find that medication there and then go back an hour or two to that patient's house to deliver it. So, the time frame, which they get their medications is also markedly slower.*
>
> *I think I've been very fortunate because the social workers that I work with and the case coordinators, we're always able to find something to patch it together [in order to get services into the home in time when death is near].*
>
> *It's finding the collaborating, either physician or nurse practitioner or family doctor who's comfortable with managing end of life, sudden symptoms and working with the team and in a team-based approach. So, um, if they weren't trained in, in a team-based approach or trained in hospice and palliative medicine, they might not feel comfortable ordering morphine or*

some of the other medications that need to be ordered or managing terminal delirium, which is a very complex challenging syndrome to manage.

Facilitators to hospice delivery. Study participants also described facilitators to hospice delivery. Though they described facilitators on a much smaller scale as compared to barriers. The main facilitators focused on practitioners who were dedicated to hospice care and delivering the highest quality care regardless of where the patient resided. Participants who had access to telehealth found this a very useful service in rural Pennsylvania, and those participants who did not have access to telehealth described this as an area of future improvement. Participants also described a "sense of community" in rural areas and the importance of that community, especially for rural patients who lived alone or did not have family in the area. The facilitators were framed in the context of rural Pennsylvania but may have broader implications to include all patients receiving hospice. The following quotes highlight the theme of facilitators to hospice delivery.

So we provide the same type of hospice services to all patients regardless of where they live. That includes, if necessary, if they requested aid services, social work chaplain. I think it might just be difficult occasionally to schedule those services because they do have to drive so far out. I don't think it impairs the amount of services they receive because we just have to make it work as you know what I mean? Our patients are promised the care that we provide and that has to be equivalent amongst all patients.

The sense of community, the church in that area so that, that church has trained caregivers ready to coach families through these situations and they're available. I definitely think having people in those rural communities is essential. And I think we need to think outside the box because there aren't enough healthcare providers to do this kind of work regardless of geographic location.

As I talked about earlier, the telemedicine piece or the telehealth support is essential, I think it needs to be upped. But we need to figure out the lack of cellular service.

Areas of improvement. Study participants had many suggestions on how to improve hospice delivery to rural patients and their families. Inherently, many of these areas for improvement hinged on addressing many of the barriers and building upon the facilitators identified above.

Participants also highlighted areas of improvement, such as loan forgiveness programs specific to hospice and palliative medicine delivery for all licensed providers. Participants also highlighted the need for across-the-board improvements in how practitioners are educated to deliver hospice care ranging from pre-licensure educational programs to post-licensure continuing education programs. Many study participants linked a lack of training and education to the high rates of burnout and staff turnover in hospice.

> *We need better standardized education for hospice and palliative care—competency based education even like, checklists and confirmation of [basic competencies for hospice-specific care. So what we're trying to improve, how we educate our staff and then making sure that there's touch points with them that are not just once during orientation.*

In summary, the study participants, who were all hospice and palliative medicine providers who delivered care to rural Pennsylvania residents, highlighted significant challenges to their ability to provide high quality care to some of the most vulnerable patients. The most salient issue identified from this inquiry is the significant delays in end-of-life care to residents residing in rural counties. Timely care is important for all patients who require end-of-life services, and critically important for those who have distressing symptoms at the end of life. These findings generate future areas of research and provides data that can inform current practice and policy.

Conclusions

1. Comprehensive description of hospice users in rural Pennsylvania

The majority of hospice users in rural Pennsylvania are older, white females. The majority of hospice care received by rural Pennsylvanians is home-based. In rural counties, males use hospice at a lower rate than females, and the difference in hospice use rates between men and women has remained stable since 2006. White decedents have the highest rates of hospice use among all racial/ethnic groups, though the gap between hospice use rates among different

racial/ethnic groups has decreased slightly since 2006. Hospice use rates also correspond with decedent age – hospice use rates increase as decedent age increases. Each of these observations are true for urban Pennsylvania counties as well.

2. Analysis of how hospice use has changed in rural Pennsylvania over recent years

There was an overall decrease in the number of hospice providers, including a 5.3 percent decrease in rural counties. Many rural counties are serviced by only a single hospice provider, and, in 15 counties, there is no hospice provider physically located in the county, further highlighting issues related to travel time for hospice staff or patients/families. Generally, the research found lower hospice use rates among rural patients, which seems to be related to the availability of hospice providers. For instance, those counties serviced by three or more hospice providers had higher average rates of hospice use than those serviced by just one or two hospice providers. Further, 100 percent of counties with three or fewer hospice providers were rural, and, with the exception of seven counties (Blair, Centre, Clearfield, Jefferson, Mercer, Mifflin, and Pike), all rural counties served by four or more hospice providers bordered non-rural counties. However, while hospice use rates were generally lower in rural counties, there were similar patterns of use between rural and urban areas – namely higher hospice use rates for female, white, older, and Medicare Advantage beneficiaries. From 2006 to 2016, there were increases in Medicare hospice use rates for every county except one. Most counties saw double-digit increases. Interestingly, the counties with the largest percent increase in hospice use were rural.

3. Analysis of future demand for hospice care in rural Pennsylvania

Overall, there was an increase in county-level hospice use rates between 2006 and 2016, with the exception of Montour and Lackawanna counties. Rates in many of these counties continued to be lower than national and state averages and thus may continue to rise. Nevertheless,

assuming similar patterns of hospice use rates in future years, and, based on projections for an aging population in rural Pennsylvania counties, the research indicated that there will be significant increases in future hospice demand. This is of particular importance to researchers and policymakers as the results of the study interviews suggest that rural Pennsylvania hospices are already experiencing substantial staffing and provider shortages. That is, these staffing and provider shortages may be exacerbated by increasing demand.

4. Identification of challenges and opportunities to providing hospice services in rural Pennsylvania as perceived by hospice providers

Interviews with stakeholders – namely providers of hospice care in rural Pennsylvania – validated concerns related to travel time, and lack of choice for patients and families. They also highlighted issues related to using electronic health records in areas with poor internet or cell service. Additionally, the majority of rural hospices were home-based, which has important implications for how care can be delivered: home-based hospice care requires substantial travel time to a patient's place of residence, adding to overhead costs for hospices and delayed care for patients. Further, home-based hospice has implications for patients and families as it requires the majority of care to be provided by an in-home caregiver (such as a family member), with only periodic visits from hospice staff. Not all patients will have an available family member to provide needed care. Inpatient hospice facilities are an option for patients without an available family member to assist with care, however, the interviews and analysis of hospice availability in rural Pennsylvania revealed that there are very few hospice facilities in rural Pennsylvania.

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