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WWAMI • ruralhealth researchcenter
UNIVERSITY of WASHINGTON

Palliative Care Challenges and Solutions in Rural U.S. Communities

KEY FINDINGS

The following key findings from this study of palliative care (PC) in rural communities in the U.S. are based on two surveys of hospitals and interviews with administrators and PC clinicians at small rural hospitals. PC is defined as interdisciplinary care to increase comfort and quality of life for patients with serious illness. PC differs from hospice care which is time-limited and provided specifically for patients with terminal illness when curative treatment has been discontinued.

- A smaller proportion of rural than urban hospitals (69.1% vs. 75.9%) responding to the 2020 American Hospital Association Annual Survey reported providing PC services.
- In a 2022-2023 survey of rural hospitals, more than a third (37.3%) reported that accessing PC services was somewhat or very difficult for patients in their community. Of the rural hospitals that reported providing one or more PC services, the most common services were pain and symptom management (90.1%); clarification of goals of care (84.7%); and physical, speech and/or occupational therapy (84.3%).
- Rural counties without hospital-based PC services (compared to rural counties with) had significantly higher proportions of socioeconomically disadvantaged populations in terms of higher poverty rates and lower levels of education.
- PC services were inequitably distributed across rural counties according to racial composition. On average, rural counties overall without hospital PC services had greater proportions of Black and American Indian/Alaska Native residents than rural counties with hospital PC services.
- Survey respondents most frequently reported the following major or minor barriers to providing PC services: dispersed geography (78.2%), inadequate PC workforce (73.0%), and inadequate PC workforce training (69.2%). These challenges were echoed in interviews with personnel from 14 small rural hospitals.
- Interviewees reported that key facilitators to offering rural hospital PC services were community collaboration, the availability of informal support networks, and staff willingness to develop and employ innovative methods to deliver services. Affiliation with larger urban health care systems that offer PC services could also provide valuable resources and support for rural hospitals that wish to offer PC services in their communities.

BACKGROUND

Palliative care (PC) is interdisciplinary, person-centered care that aims to increase comfort and quality of life for patients with serious illness.[1] PC includes physical, emotional, social, and spiritual aspects of care for patients and their caregivers. PC and hospice care are sometimes conflated. While hospice care can include palliative measures and is a type of PC, the two are distinct in important ways.[2-4] Hospice care is time-limited and provided specifically for patients with terminal illness, generally in the last six months of life and when curative treatment has been discontinued. Hospice care typically, though not always, occurs outside hospital settings, including in inpatient hospice facilities. In contrast, palliative care is not time-limited and is appropriate alongside curative or life-prolonging care at any stage, in all settings, and at any age. Palliative care is often provided in hospitals, but it can also be delivered in community settings, such as clinics, nursing homes, assisted living facilities, and an individual's personal home.

Rural populations face unique challenges to accessing PC services including long distances and lack of transportation, lack of PC healthcare professionals and resources, limited availability of primary or specialist-level PC, and cultural and social differences that may affect care.[5-7] No comprehensive national information exists on the prevalence of PC services in rural hospitals and communities. Understanding the unique needs and innovations of rural communities in providing PC services can inform policy initiatives to ensure that rural populations have access to health services that improve quality of life for patients and their caregivers, while reducing costs.

This study seeks to describe the availability of PC services in rural compared with urban hospitals and document emerging PC solutions for rural communities. We sought to answer four research questions: (1) How available are PC services in rural compared with urban hospitals across the U.S., nationally, regionally, and by level of rurality? (2) How equitably are PC services distributed within rural areas according to community characteristics such as poverty, education, employment level, as well as racial and ethnic composition of the population? (3) What PC services are offered through rural hospitals, health systems, and/or formal contractual arrangements? (4) How have some of the smallest rural hospitals with PC services developed and maintained these services?

METHODS

Data Sources

This mixed-methods study used three data sources as described below. The University of Washington Human Subjects Division approved the study as exempt research.

American Hospital Association (AHA) Annual Survey. We used 2020 AHA survey data for descriptive analyses of PC services at all 4,065 rural and urban hospitals in the 50 U.S. states and District of Columbia that responded to relevant questions.*

We used either ZIP code or county-based rural definitions depending on the geographic location classifications available in the various data sources. We used hospital ZIP codes to categorize hospital locations as urban and three categories of rural according to Rural-Urban Commuting Area (RUCA) codes as follows: (1) urban: RUCA codes 1.0, 1.1, 2.0, 2.1, 3.0, 4.1, 5.1, 7.1, 8.1, 10.1; (2) large rural: 4.0, 5.0, 6.0; (3) small rural: 7.0, 7.2, 8.0, 8.2, 9.0; and (4) isolated small rural: 10.0, 10.2, 10.3.[8] We merged AHA data with 2019 county racial and ethnic composition data from the Area Health Resources File[9] and 2015 U.S. Department of Agriculture (USDA) Economic Research Service (ERS) County Typology codes, which include measures

* We excluded 72 hospitals outside of the 50 U.S. states and DC and 2,028 hospitals that provided no data on PC services.

of income, poverty, education, and employment.[10†] County analyses used five Urban Influence Code (UIC) categories: (1) metropolitan: UICs 1, 2; (2) adjacent micropolitan: UICs 3-7; (3) nonadjacent micropolitan: UIC 8; (4) small rural: UICs 9, 10; and (5) remote small rural: UICs 11, 12.[11]

Survey of rural hospitals. With input from experts in palliative care, we developed a 120-item, web-based survey instrument with questions about inpatient and outpatient PC services offered through the hospital, the health system, and/or formal contractual arrangements; funding for hospital PC services; types of personnel that provide hospital PC services; barriers to providing PC services in rural areas; and availability of hospice services. We directed our survey to the most appropriate person at each hospital who could respond to a survey about PC services (medical or nursing directors or officers, hospital chief operating officers, hospital chief financial officers, or hospital personnel identified as administering or providing services for hospice, PC, or end of life). Through a combination of mailed push-to-web paper surveys and invitations, emailed invitations with a survey link, and phone calls, we made up to four contact attempts from December 2022 through May 2023 to all 2,013 long-term care and general medical and surgical hospitals identified as rural according to RUCA codes in the AHA dataset.

Interviews with rural hospital personnel. Using data from AHA and our survey of rural hospitals, we invited administrators of rural hospitals or health systems with 50 beds or fewer that offered PC services to participate in 45- to 60-minute confidential videoconference interviews, seeking geographic diversity by U.S. Census Region. The semi-structured interview guide included 16 open-ended questions about PC services offered; use of contract arrangements; PC service settings; use of telehealth; barriers to, and facilitators of, offering hospital PC services in rural areas; and advice for other rural hospitals interested in starting a PC service. We conducted, audio-recorded, and transcribed interviews from February through June 2023.

Analysis

We used Stata 14.0 to calculate descriptive statistics and chi-square or t-tests as appropriate for survey analyses, at either the $P<.05$ or $P<.01$ (to adjust for multiple comparisons) thresholds for statistical significance. We used directed content analysis[12] to derive key themes from interviews.

RESULTS

We report results first from the AHA Annual Survey, followed by the survey and interview results from rural hospitals.

AHA Annual Survey

The 2020 AHA Annual Survey response rate was 66.1%.[‡]

Availability of PC services. A slightly smaller proportion of rural than urban hospitals reported providing any PC services (69.1% vs. 75.9%, respectively, $P<.05$), which could include hospice, outpatient PC programs, and/or inpatient PC care units (Figure 1). A much lower proportion of rural hospitals, two-fifths (40.8%), reported having a PC program compared to two-thirds (67.0%) of urban hospitals. Nearly two-thirds of both rural (61.8%) and urban (65.7%) hospitals provided hospice services. The Appendix provides estimates for hospitals in urban areas and large, small, and isolated small rural areas.

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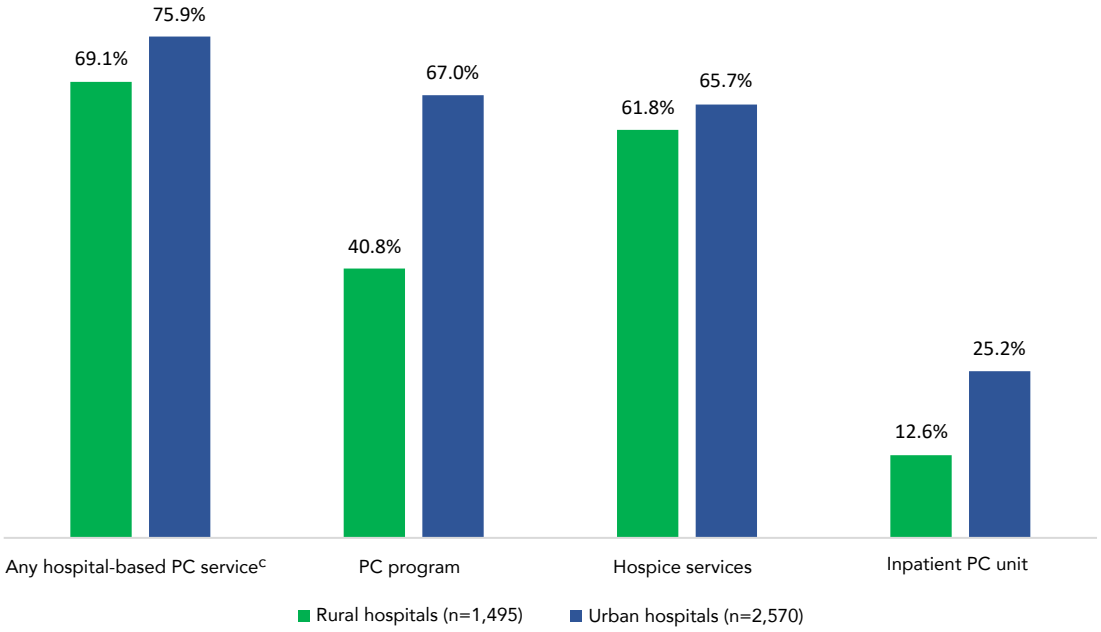
†The USDA ERS defines low-employment counties as those where less than 65 percent of residents 25-64 years old were employed in 2008-2012 (5-year average). Low-education counties are those where 20 percent or more of residents 25-64 years old had neither a high school diploma nor GED in 2008-2012 (5-year average). Persistent-poverty counties are those where 20 percent or more of residents were poor as measured by each of the 1980, 1990, 2000 censuses, and 2007-2011 American Community Survey (5-year average). Per capita income estimates are based on the 2020 census.

‡A. Vincent, American Hospital Association, personal communication, April 12, 2024.

Figure 1. Hospital Palliative Care (PC) Services, by Urban-Rural Designation, 2020[a,b]



Data source: 2020 American Hospital Association Annual Survey
Rural-urban comparisons were significant at P<.05 for all analyses.
[a]Includes services provided in the hospital, health system, or a joint venture owned or provided by the hospital or its subsidiary, provided by the hospital's health system or through a formal contractual arrangement or joint venture with another provider in the local community.
[b]Rural-Urban Commuting Area (RUCA) codes used to define rural.
[c]Includes any hospital that reported a hospice program, palliative care services, or inpatient palliative care unit.

Sociodemographic characteristics of counties with and without hospital PC services. Counties with no hospital-based PC services had higher proportions of socioeconomically disadvantaged populations (Table 1). Compared to rural counties with at least one hospital with PC services, rural counties with no hospitals that offered PC services were more likely to be designated as having low employment (44.5% vs. 25.5%), low education (22.7% vs. 12.9%), or persistent poverty (20.4% vs. 8.1%) (P<.01 for all variables noted). Across all subtypes of rural U.S. counties (micropolitan counties adjacent and nonadjacent to metropolitan counties, small and remote small rural counties), higher proportions of counties without hospital PC services were designated as low employment and persistent poverty than counties with hospital PC services. Counties in all rural subtypes with no hospital PC also had lower per-capita incomes on average than their counterparts with hospital PC services. Higher proportions of all micropolitan counties without hospital PC services were designated as having low education than comparable counties with hospital PC services. Adjacent micropolitan, small, and remote small rural counties with no hospital PC services had higher proportions of persons below the federal poverty level than comparable counties with hospital PC services.

Rural counties with and without hospital PC services differed in racial composition. On average, rural counties overall without hospital PC services had greater proportions of Black and American Indian/Alaska Native residents than rural counties with hospital PC services. Micropolitan counties adjacent to metropolitan counties with no hospital-based PC services had higher proportions of Black or African American residents compared to counties with at least one hospital with PC services (12.1% vs. 7.6%). Similarly, remote small rural counties with no hospital PC services had higher proportions of American Indian/Alaska Native residents compared to remote small counties with at least one hospital with PC services (9.3% vs. 3.4%).

Table 1. Sociodemographic Characteristics of Urban (Metropolitan) and Rural (Non-Metropolitan) Counties With and Without One or More Hospitals With Palliative Care (PC) Services,[a,b] 2020

County characteristic (mean %, except as noted)	Metropolitan N=1,166		All non-metropolitan N=1,976		Non-metropolitan							
					Adjacent micropolitan N=1,027		Nonadjacent micropolitan N=269		Small rural N=373		Remote small rural N=307	
	Counties with no hospital PC services (N=418)	Counties with ≥1 hospital with PC services (N=748)	Counties with no hospital PC services (N=1,140)	Counties with ≥1 hospital with PC services (N=836)	Counties with no hospital PC services (N=559)	Counties with ≥1 hospital with PC services (N=468)	Counties with no hospital PC services (N=127)	Counties with ≥1 hospital with PC services (N=142)	Counties with no hospital PC services (N=258)	Counties with ≥1 hospital with PC services (N=115)	Counties with no hospital PC services (N=196)	Counties with ≥1 hospital with PC services (N=111)
Race												
White	**83.7%**	**81.0%**	**83.8%**	**88.5%**	**82.4%**	**87.7%**	85.1%	86.7%	**87.1%**	**91.3%**	**82.7%**	**91.4%**
Black or African American	11.3%	11.8%	**9.3%**	**6.3%**	**12.1%**	**7.6%**	9.5%	6.7%	7.3%	4.0%	4.0%	2.2%
American Indian/ Alaska Native	1.3%	1.1%	**3.8%**	**2.1%**	2.7%	1.8%	2.4%	2.0%	2.9%	2.1%	**9.3%**	**3.4%**
Asian	**1.4%**	**3.5%**	0.8%	1.0%	**0.8%**	**0.9%**	0.9%	1.7%	0.6%	0.7%	1.4%	0.8%
Native Hawaiian/ Other Pacific Islanders	0.3%	0.2%	0.1%	0.1%	0.1%	0.1%	0.1%	0.3%	0.1%	0.1%	0.1%	0.1%
Two or more races	**2.2%**	**2.5%**	2.1%	2.0%	2.0%	1.9%	1.9%	2.5%	2.0%	1.8%	2.6%	2.0%
Ethnicity												
Hispanic or Latino	**7.2%**	**12.3%**	9.6%	9.1%	9.1%	8.7%	10.9%	10.7%	9.3%	8.5%	10.4%	9.3%
Socioeconomic characteristics												
Low education[c]	**12.0%**	**6.7%**	**22.7%**	**12.9%**	**24.0%**	**13.0%**	**26.8%**	**11.3%**	20.9%	18.3%	18.9%	9.0%
Low employment[d]	**27.8%**	**9.4%**	**44.5%**	**25.5%**	**49.7%**	**30.3%**	**38.6%**	**14.8%**	**44.2%**	**27.8%**	**33.7%**	**16.2%**
Persons below federal poverty level[e]	**13.9%**	**13.0%**	**17.1%**	**15.0%**	**17.7%**	**15.3%**	**16.6%**	**15.4%**	**16.6%**	**14.5%**	**16.4%**	**13.6%**
Persistent poverty[f]	6.2%	3.5%	**20.4%**	**8.1%**	**18.8%**	**8.3%**	**22.0%**	**7.0%**	**23.3%**	**11.3%**	**20.4%**	**5.4%**
Per capita income, 2020 median	**$42,456**	**$48,535**	**$40,014**	**$43,297**	**$38,942**	**$42,277**	**$39,915**	**$43,578**	**$40,848**	**$45,887**	**$45,205**	**$48,853**

Data sources: 2020 American Hospital Association (AHA) Annual Survey, Area Health Resources Files 2020-2021 County-Level Data.
Bold values are significant at P<.01 and compare counties with and without PC services within each Urban Influence Code (UIC) designation.
[a]Includes any hospital that reported providing a hospice program, palliative care (PC) services, or inpatient PC unit, including services provided in the hospital, health system, or a joint venture owned or provided by the hospital or its subsidiary, provided by the hospital's health system in the local community, or provided through a formal contractual arrangement or joint venture with another provider in the local community.
[b]UICs classify counties as follows: (1) metropolitan: UICs 1, 2; (2) adjacent micropolitan: UICs 3-7; (3) nonadjacent micropolitan: UIC 8; (4) small rural: UICs 9, 10; (5) remote small rural: UICs 11, 12.
[c]Low education: 20% or more of residents 25-64 years old had neither a high school diploma nor GED in 2008-12 (5-year average).
[d]Low employment: Less than 65% of residents ages 25-64 were employed in 2008-2012 (5-year average).
[e]Percent of county population below the federal poverty level (FPL), 2016-2020 U.S. Census.
[f]Persistent poverty: 20% or more of county residents were poor as measured by each of the 1980, 1990, and 2000 censuses and 2007-11 American Community Survey 5-year average.

Characteristics of hospitals with PC services. A majority of both rural and urban hospitals that provided PC services were non-profit, though rural hospitals were less often non-profit than urban hospitals (rural, 65.5% vs. urban, 74.7%, P<.01) (Table 2). Rural hospitals with PC services were most often small, up to 25 beds (43.2%), and 54.5% were Critical Access Hospitals. About a third of rural hospitals with PC services had 51 to 200 beds. Rural hospitals with PC services were more often owned and operated by non-federal government entities (28.6%) compared to urban hospitals (10.6%), while a smaller proportion of rural hospitals were for-profit, investor-owned (rural, 5.6% vs. urban, 13.5%). Most rural hospitals with PC services also had swing bed services (70.4%) and pastoral care (71.0%).

Table 2. Characteristics of Rural and Urban Hospitals Reporting Hospital Palliative Care Services,[a,b] 2020

			Rural		
	Urban N=1,925	All rural N=1,033	Large rural N=429	Small rural N=401	Isolated small rural N=203
Census region					
Northeast	**17.4%**	**9.7%**	10.7%	9.7%	7.4%
Midwest	**24.7%**	**47.4%**	40.1%	47.9%	62.1%
South	**40.2%**	**28.7%**	33.1%	29.2%	18.2%
West	**17.8%**	**14.2%**	16.1%	13.2%	12.3%
Hospital type					
Critical access hospital	**4.4%**	**54.0%**	20.8%	71.3%	90.2%
Rural referral center	**19.5%**	**5.2%**	11.7%	0.8%	0.5%
Sole community provider	**1.5%**	**14.7%**	20.8%	13.5%	4.4%
Number of beds					
0-25	**5.7%**	**43.2%**	16.6%	59.4%	67.5%
26-50	**7.1%**	**16.7%**	20.1%	15.2%	12.3%
51-200	**34.8%**	**34.2%**	50.6%	24.2%	19.2%
>200	**52.5%**	**6.0%**	12.8%	1.3%	1.0%
Ownership/administration[c]					
Government, nonfederal	**10.6%**	**28.6%**	21.9%	29.9%	39.9%
Government, federal	**1.5%**	**0.3%**	0.5%	0.3%	0.0%
Not-for-profit	**74.7%**	**65.5%**	68.5%	66.1%	58.1%
For-profit, investor-owned	**13.3%**	**5.6%**	9.1%	3.7%	2.0%
Hospital services[d]					
Swing bed services[e]	**22.6%**	**70.4%**	45.7%	85.3%	93.1%
Geriatric services	**74.3%**	**48.3%**	52.7%	45.4%	44.8%
Pastoral care	**94.1%**	**71.0%**	83.0%	65.1%	57.1%

Data source: 2020 American Hospital Association (AHA) Annual Survey.
Comparisons of urban and "all rural" categories were significant at P<.01 for all analyses.
[a]Rural-urban designations are based on Rural-Urban Commuting Area (RUCA) codes.
[b]Includes any hospital that reported providing a hospice program, palliative care services, or inpatient palliative care unit, including services provided in the hospital, health system, or a joint venture owned or provided by the hospital or its subsidiary, provided by the hospital's health system in the local community, or provided through a formal contractual arrangement or joint venture with another provider in the local community.
[c]Indicates the type of organization responsible for establishing policy for overall operations of the hospital: government, nonfederal includes state, county, city, city-county, hospital district or authority; government, federal includes Department of Defense, Public Health Service (PHS), Veterans' Affairs, other federal, PHS Indian Service, Department of Justice; non-government, not-for-profit (NFP) includes church-operated and other NFP entities, including NFP corporations; investor-owned, for-profit includes individual partnership or corporation ownership.
[d]Includes services through the hospital, health system, or joint venture.
[e]Swing beds are defined as hospital rooms that can switch from in-patient acute care status to skilled care.

Survey of Rural Hospitals

Of 2,013 hospitals invited to the survey, 164 (8.1%) responded. Among responding hospitals, 14.3% reported providing comprehensive PC services, defined as operating their own interdisciplinary inpatient and/or outpatient PC services including physical, emotional, social, and spiritual care, while 28.0% reported providing some (but not comprehensive) PC services (Table 3). More than half (57.8%) of responding hospitals did not operate any PC services of their own, while nearly one-fifth (17.9%) reported providing PC services through formal contractual arrangements.

Table 3. Availability of Hospital Palliative Care (PC) Services in Rural U.S. Hospitals and Health Systems, 2022-2023

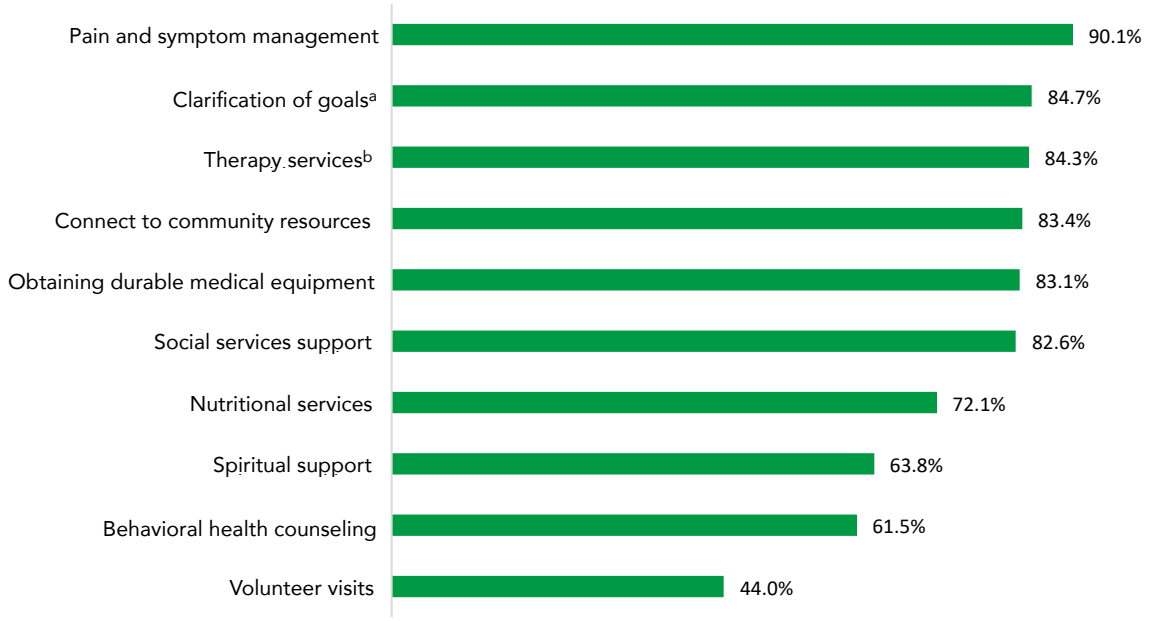
	Large rural N=48	Small rural N=71	Isolated small rural N=45	Total N=164
Hospital operates its own PC services[a]				
Yes, provides comprehensive PC services	24.4%	11.3%	8.9%	14.3%
Yes, provides some PC services	26.7%	28.2%	28.9%	28.0%
No, does not operate own PC services	48.9%	60.6%	62.2%	57.8%
PC services provided through formal contractual arrangement				
Yes	28.2%	12.1%	17.5%	17.9%
No	71.8%	87.9%	82.5%	82.1%
When a patient needs PC services that the hospital does not provide, the hospital…				
Provides contact information for PC services	65.9%	81.0%	76.7%	75.3%
Refers patients to PC services outside local community	67.4%	67.2%	69.8%	68.0%
Refers patients to PC services in local community	67.4%	67.7%	54.5%	63.9%
Does not know where to send patients for PC services	16.3%	16.1%	17.5%	16.6%
Does not refer/provide contact information for PC services	11.6%	11.3%	11.9%	11.6%
Hospital able to help patients access needed PC services				
Always or usually	65.9%	68.2%	57.5%	64.7%
Sometimes	25.0%	21.2%	25.0%	23.3%
Seldom or never	9.1%	10.6%	17.5%	12.0%
Ease of access to PC services among patients in community				
Very or somewhat easy	38.6%	40.0%	41.5%	40.0%
Neither easy nor difficult	27.3%	21.5%	19.5%	22.7%
Somewhat or very difficult	34.1%	38.5%	39.0%	37.3%

Data sources: WWAMI Rural Health Research Center survey. Rural designations are based on Rural-Urban Commuting Area (RUCA) codes.
NOTES: There were no statistically significant differences at P<.05 between rural categories for any item. Missing and "don't know" values excluded from the analysis: hospital operates its own PC services 3, contractual arrangement 19, PC services that the hospital does not provide (refer patient in local community 9, refer patients outside community 11, provide contact information 14, do not know where to send patients 19, do not refer 17), hospital able to help patient access PC 14, ease/difficulty for patients to access PC services 14.
[a]Question specifies inpatient or outpatient PC services offered to the local community through the hospital or health system.

When a patient needed PC services not provided by the hospital, three-quarters of hospitals (75.3%) reported that they provided contact information for PC services, and about two-thirds referred patients to PC services outside the local community (68.0%) or within the local community (63.9%) (Table 3). Some hospitals (16.6%) reported that they did not know where to send patients for PC services. Reasons cited for not offering these services included lack of PC expertise among staff (62.3%), cost (37.3%), other providers in the community already offered PC services (39.1%), lack of familiarity (45.8%) and low demand (34.8%) for PC services among providers, and lack of familiarity (40.8%) and low demand (31.4%) for PC services among patients and families (data not tabled).

Pain and symptom management, clarification of goals of care, and physical, speech and/or occupational therapy were the most common PC services offered (Figure 2). Less commonly offered were spiritual support, behavioral health services, or volunteer visits. Among hospitals offering PC services, 30.4% offered hospice only, 13.9% offered only non-hospice PC services, and 44.3% offered both hospice and PC services (data not shown).

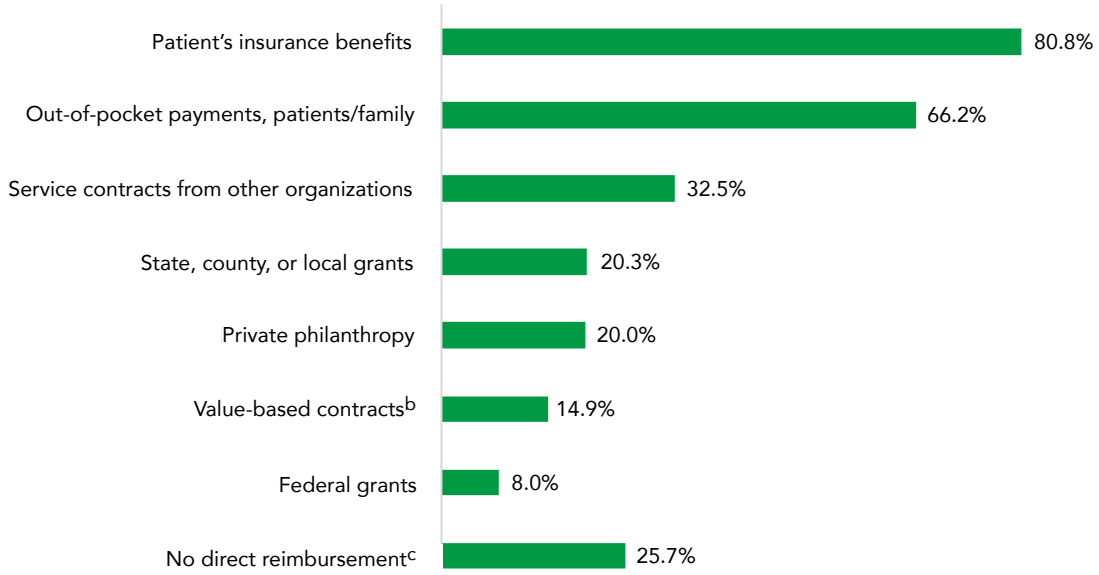
Figure 2. Rural Palliative Care Services Offered Through a Hospital or Health System and/or Through Formal Contractual Arrangement, 2022-2023 (N=82)



Data source: WWAMI Rural Health Research Center survey. Rural-urban designations are based on Rural-Urban Commuting Area (RUCA) codes.
Notes: Palliative care services were offered inpatient or outpatient in the local community.
[a]Care goals: Includes advance care planning or completion of POLST (Physician Orders for Life-Sustaining Treatment) forms.
[b]Therapy services: Occupational, physical, and/or speech/language therapy.

Top funding sources for PC services included patients' insurance benefits (reported by 80.8% of hospitals), out-of-pocket payments by patients and families (66.2%), and service contracts from other organizations (32.5%) (Figure 3). A fifth of hospitals relied on state, county, or local grants (20.3%) and/or philanthropy (20.0%). About a quarter (25.7%) of hospitals reported that PC services are considered part of the hospital's operating expenses and they do not receive any direct reimbursement for these services.

Figure 3. Funding Sources for Palliative Care Services Offered by Rural[a] Hospitals, 2022-2023 (N=82)



Data source: WWAMI Rural Health Research Center survey.
Notes: Question asked only of respondents that offered PC services through their hospital/health system or through formal contractual arrangements (N=82).
[a]Rural-urban designations are based on Rural-Urban Commuting Area (RUCA) codes.
[b]Value based contracts included Accountable Care Organization participation.
[c]No direct reimbursement: PC services considered part of hospital operating expenses.

Table 4. Major and Minor Barriers That Rural Hospitals or Health Systems Experienced When Providing Palliative Care (PC) Services, 2022-2023 (N=164)

Barriers	Major barrier	Minor barrier	Not a barrier	Not applicable, don't know/not sure
Inadequate PC workforce	47.4%	25.6%	14.7%	12.2%
Geography (patients are distant from PC services)	37.2%	41.0%	10.3%	11.5%
Inadequate PC training	36.5%	32.7%	15.4%	15.4%
Budget constraints (eg, insufficient reimbursement)	36.5%	24.4%	17.3%	21.8%
Lack of community knowledge about PC services	27.2%	34.8%	20.9%	17.1%
Competing priorities for organization	23.4%	26.6%	33.1%	16.9%
Managing the complexity of interdisciplinary PC services	22.3%	36.3%	23.6%	17.8%
Patients' lack of internet access	16.9%	42.9%	23.4%	16.9%
PC services only available inpatient, not outpatient	13.5%	17.9%	27.6%	41.0%
Health care providers' perceived lack of need for PC services	12.1%	19.7%	46.5%	21.7%
Lack of leadership support for PC services	7.8%	15.7%	55.6%	20.9%
Clinical staff reluctance	7.7%	26.3%	48.1%	17.9%

Data source: WWAMI Rural Health Research Center survey. Rural-urban designations are based on Rural-Urban Commuting Area (RUCA) codes.
NOTE: Missing survey responses: Inadequate PC workforce 8, geography 8, inadequate PC training 8, budget constraints 8, lack of community knowledge 6, competing priorities 10, complexity of interdisciplinary PC services 7, lack of internet access 10, PC inpatient services only 8, providers' perceived lack of need 7, lack of leadership support 11, clinical staff reluctance 8.

Interviews with Rural Hospital Personnels

To better understand how smaller rural hospitals with 50 beds or fewer were providing PC services, we interviewed administrators at 14 rural hospitals. PC clinicians joined administrators in two (of the 14) interviews, and several interviewees held dual roles as an administrator and clinician. The 14 hospitals were distributed across U.S. Census Regions as follows: West (6), Midwest (4), South (3), and Northeast (1). Below and in Box 1 we summarize barriers, facilitators, and recommendations for developing and maintaining PC services as described by interviewees.

Most of the hospitals provided PC services directly, but three hospitals contracted with outside agencies to provide hospice and/or PC services. Among the hospitals interviewed, PC service settings included inpatient care, outpatient clinics, home-based services, and hospital-based clinics.

Barriers

Geography. All interviewees noted geography as a barrier to providing PC services. A director of nursing at a remote hospital with a service area of approximately 2,000 square miles noted that, "The closest palliative care service is 2.5 hours from here. There is only one other hospital between us [and the PC service], and that is a Critical Access Hospital (CAH) which is one hour and 20 minutes away."

Interviewees described how a lack of reliable high-speed internet in many geographically remote areas affected providers' ability to deliver PC services. An interviewee at a remote CAH noted that patients in her service area often need to come into the hospital to get internet connections for telehealth services. During a conversation about challenges with telehealth mental health referrals, a chief nursing officer (CNO) noted that given the unreliable technology "you can't just FaceTime" when someone is in crisis or would benefit from virtual health care. Cell phone deserts were also noted by several interviewees.

Finance. Financial sustainability and reimbursement were frequently mentioned as challenges. One interviewee said, "We're keeping people out of the ER by providing PC services, which is the goal, but then the hospital loses the $7000." Some hospitals had developed workarounds. A CNO described how PC may not be profitable but can be subsidized by more profitable services such as surgery. She said, "We're losing money on palliative care as a stand-alone, it's not profitable. Because we're an independent Critical Access Hospital, a small organization, we're fortunate that the decision makers are vested in the community, [they are] part of the community. We have always maintained that if we can break even, we're going to provide services to best of our ability […]. Surgery helps to subsidize palliative care. If we can balance out with other things, we are going to do that."

Mistrust of institutions. Several interviewees mentioned community skepticism of institutions, including health care establishments, and the resulting impact on providers' ability to deliver services. One CNO noted, "In very rural communities, sometimes there is a mistrust of health care in general. A lot of people associate it with government, big government, especially through the COVID crisis, different mindsets about how to treat. That type of culture doesn't bode well for people trying to provide health care in those circumstances."

Box 1. Barriers, Facilitators, and Recommendations for Hospital Palliative Care Services in Rural Areas Reported by Rural Hospitals Interviewees

Barriers	Facilitators
Geography	Teamwork
Finance	Informal arrangements
Mistrust of institutions	Collaborations with community partners
Lack of community knowledge	
Staffing	

Recommendations
Get hospital leadership and provider buy-in
Cultivate relationships with community partners
Identify and work with consulting clinicians who have PC expertise
Identify and develop a champion
Leverage existing services
Consider contracting
Have a plan and start slowly

Lack of community knowledge. Interviewees described how some patients and families may think that entering hospice or PC is an indication that the medical staff have given up on the patient, "a belief that nothing is going to be done any more." Another noted, "I saw a huge shift in this community [in relation to providing PC services], when a few elections ago there was talk about the death panels. It was like a light switch flipped. …it's a long haul to come back from that." She noted, however, that people are more accepting of PC services than hospice.

Staffing. Approximately half of the interviewees relayed that staffing was a challenge, including staffing shortages in general and also lack of staff with PC expertise. Others did not face staffing shortages. Several interviewees noted that long-term retention was higher among staff who lived in the community and those with rural backgrounds. Only three hospitals had designated PC staff. More often, staff without a designated PC role provided PC services during inpatient stays. A variety of strategies were used to recruit and retain staff including managing workloads and wage increases. Several hospitals described the challenge of balancing competitive wages and staying within a budget. One nursing director commented, "Wages have gone up for nurses a lot too. When you have a small budget and not a lot of revenue …[we] would love to pay more, but it's not a reality to keep our doors open."

Facilitators

Despite many challenges, interviewees described a high degree of community collaboration, innovation, and creativity which often facilitated the provision of high-quality services even in hospitals without formal PC programs.

Teamwork. The theme of pitching in and team effort came up repeatedly. Many interviewees commented that they or their staff were from the community and committed to the patients that they served and often played multiple roles, as one interviewee noted: "With so few [home health or hospice] agencies, everyone does double duty. We're the fireman, the hospital, the policeman, and everyone just does what has to get done. It's just a tight-knit community and everyone wants to help patients in our community. The community recognizes the need."

Informal arrangements. Another common theme was the need to "think outside the normal boxes" and operate outside formal systems in order to provide needed services or resources, sometimes without monetary compensation. Another noted that for patients needing equipment for home accessibility, "There's a person in town who has a metal ramp that [the hospital staff] move around town when patients need it."

In small communities, where health care providers usually know their patients outside the hospital walls, staff often do unpaid work for patients needing PC services. For example, an interviewee in a frontier rural area described how she and other nursing staff frequently made unpaid home visits: "We currently have a patient in our community that wants to stay home. …I have gone to his home and other patients' homes and helped them get into bed or to do a bath, and our nurses will just go and help patients if they need help." Others described similar scenarios of uncompensated care for patients. These informal solutions could constitute both challenges, since ideally providers should be paid for their work, and facilitators that demonstrate providers' commitment to their patients and a sense of shared responsibility for the community's welfare.

Collaborations with community partners. Interviewees described a range of non-contractual PC services provided through partnerships with community organizations (eg, Meals on Wheels). The benefits of working closely with community partners went beyond service provision. Community partners that see patients in their home may have insights into patients' living conditions that would not be apparent at a clinic visit, and these concerns can be conveyed to hospital staff. One interviewee said, "The county pays for transport to doctor's service and those services allow us to keep a closer eye on the patient in their home. We have conversations [with the transport service] around whether we need to consider more involvement [in the patient's care]. Our town is small, about 350 people, and they're scattered about in a huge geographical space. We don't see [patients] in the hospital until we have a big problem."

Recommendations and Lessons Learned

Interviewees shared wide-ranging insights for other hospitals interested in developing PC services, which are summarized below.

Get hospital leadership and provider buy-in. Several interviewees noted the importance of early involvement and buy-in of key parties including providers and administration. One CNO relayed, "It's very important to get buy-in from a great many areas for it [a new PC program] to be successful. [Buy-in] from admin to understand that [PC services] are not going to be a money-maker and they're okay with that…it's really a community service and not going to line your bottom line. But you have to have buy-in to break even or even lose a little money. Also, with physicians. If you don't have their buy-in, it's not going to be successful."

Another interviewee, when describing challenges in staff acceptance of their PC program, said, "I think what we should have done and would have gotten more buy-in is to approach the medical staff more softly and include them at the very beginning.

As administration, we came up with the policy and didn't think we'd meet resistance because it seems like a good idea in our minds. Maybe if we had included more in the beginning…I think we would have got farther, and I want to remember that lesson. I think after COVID some people aren't open to moving anymore. They just don't want any more new stuff."

Cultivate relationships with community partners. The crucial support that community partners can provide to rural PC programs came up in numerous interviews. One CNO at an independent CAH recommended assessing the facility's needs and corresponding community resources, for example, chaplain services: "Hospitals need to…see who they can partner with to make the resources available. For example, do they [the hospital] have chaplain coverage? Larger hospitals usually have a team and have 24/7 chaplain coverage. [Chaplains in rural areas] should be brought in early to initiate those discussions." Another interviewee noted, "Make sure you've got good relationships with community partners because there are many needs that have to be met. Understanding where resources are and developing good relationships can make all the difference in the world." Similarly, a chief medical officer at a remote rural CAH suggested formalizing communication between the hospital and local services in the early stages of developing a PC program.

Identify and work with clinicians who have PC expertise. Several interviewees observed that having a full-time PC clinician is often not needed and may not be realistic. In some hospitals existing clinicians had developed PC expertise and were able to provide guidance for other staff members. Others had access to external consultation resources. One interviewee said, "You really just need someone that you can consult with, you don't necessarily need a full-time employee MD. The finance people will not go for that."

Identify and develop a champion. Internal advocates can help a PC program develop and thrive, according to several interviewees. One interviewee, while describing the positive impact of the clinician leadership at her facility, noted "You really need to have someone who is really passionate about it, someone that isn't just doing a 9 to 5. You have to have someone who truly believes in what they're doing in order to succeed."

Leverage existing services. The concept of harnessing existing resources as a way to develop and grow a PC program was a recurring theme. For example, several interviewees noted that PC services can build upon existing hospital hospice programs. One interviewee said, "The hospice being part of your organization is huge. Not having that would make it take longer for everyone to get on the same page." Affiliations with larger urban health care systems that offer PC services may also provide resources and valuable support for rural hospitals that are developing PC services.

Consider contracting. Some interviewees noted that contracting out PC services to an agency, if available, can streamline many processes for rural hospitals.

Have a plan and start slowly. A director of hospice services in an independent CAH said, "Have a plan before you start. Let those who know the most develop the program and be patient." Another interviewee advised planning for immediate needs and for growth, and to first develop a plan for 20 patients, and then 50 patients. Another said, "Start slow. It's going to be a very slow process to get your feet wet and figure out what you're doing, especially for rural."

DISCUSSION

As the U.S. population ages, demand for palliative care services is growing. Research has shown that palliative care improves patient satisfaction, can reduce health care costs by preventing emergency department use, hospital admissions and readmissions, and can decrease inpatient length of stay.[13,14] Although rural populations are older and sicker on average than urban populations[15] – and thus in need of quality PC services – we found that a smaller proportion of rural than urban hospitals provide PC services, and more than a third of hospitals responding to our survey reported that accessing PC services was somewhat or very difficult for patients in their community. Furthermore, rural counties with no hospital PC services had higher proportions of socioeconomically disadvantaged populations compared to counties with at least one hospital that offered PC services.

Although our study population represented varied types of rural communities and solutions, nearly all reported providing core PC services such as pain and symptom management, clarification of goals of care, and assisting patients in obtaining durable medical equipment. Many programs also offered services such as spiritual support, connection to community resources, and social services support.

Both survey respondents and interviewees noted financial constraints. Because Medicare does not provide PC benefits, reimbursement is mainly through symptom management, provider visits, and care coordination codes, limiting which members of an interdisciplinary PC team can bill for direct services.[16] Other frequently reported barriers to developing or maintaining rural hospital PC services were limited availability of PC providers, dispersed geography, and inadequate PC training. Our results reflect previous research[17] suggesting that rural areas face unique and complex challenges to palliative care delivery. Health care personnel barriers, including lack of perceived need among providers themselves, lack of leadership support, and clinical staff reluctance, were infrequently reported as barriers, potentially reflecting providers' and health care leaders' interest in offering PC services.

Many rural areas have developed innovative solutions to providing PC services. In interviews with rural hospital personnel, we found that rural communities with hospitals that provide PC services capitalize on informal support networks, close-knit communities that provide a variety of resources, and hospital staff willingness to develop and employ innovative methods to successfully deliver services. Affiliation with larger urban health care systems that offer PC services may also provide cost savings and support, such as access to technology, training, and financing for rural hospitals that want to offer PC services.

Our key informant interviewees provided practical and real-world advice for rural hospitals that may be interested in starting their own PC services. These insights include collaborating and getting early buy-in from key parties, utilizing existing community resources, and considering contracting with PC providers. This guidance is consistent with recommendations included in resources developed by other research organizations and providers to facilitate PC services in rural communities. For example, The National Coalition for Hospice and Palliative Care, in its *Clinical Practice Guidelines for Quality Palliative Care*, offers examples of rural solutions for providing care for patients experiencing serious illness.[18] Stratis Health has developed rural community palliative care models and resources, including reimbursement strategies and using the Extension for Community Health Outcomes (ECHO) approach of remote expert consultation to support local services.[16,19,20] The Washington Rural Palliative Care Initiative provides extensive clinical tools and standards to assist rural health systems in integrating palliative care in multiple settings.[21]

Limitations of the current study include that AHA survey data relies on the voluntary participation of hospitals, and about two-thirds did not respond, and some questionnaire items can be skipped. [22-24] It is also possible that rural areas may be underrepresented. AHA data on hospital PC services and those offered through formal contractual arrangements were

missing for nearly a third of respondents. A significant study limitation is the low response rate to our survey of rural hospitals, despite numerous efforts to reach participants, which raises concerns about the generalizability of our findings. If those with PC services responded at a higher rate than those without, these services may be even less available in rural communities than our results indicate. The small numbers of respondents may also have limited our ability to find statistical differences when they actually existed. Finally, self-reported data are subject to potential bias or inaccuracies.

CONCLUSION

Hospital palliative care services were less available in rural than urban communities, and rural counties without hospital PC services were more socioeconomically disadvantaged than counties with hospital PC services. Rural counties without hospital PC services also had higher proportions of Black and American Indian or Alaska Native persons compared to rural counties with PC services. Common barriers to providing rural PC services included dispersed geography and inadequate PC workforce and training. These disparities suggest that rural communities, particularly the most disadvantaged, need increased support to develop or maintain PC services, including innovative models that are appropriate for low-resource environments. Collaboration with community organizations, use of informal support networks, consultation, and contractual models were reported as facilitators. Further research to understand the unique needs and innovations of rural communities in providing palliative care can also help inform advocacy and policy initiatives to ensure that rural populations have access to PC services that can improve quality of life while reducing costs.

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APPENDIX

Table A. Proportion of Hospitals Reporting Hospital Palliative Care (PC) Services[a,b] in Urban and Rural[c] Areas, 2020

			Rural		
	Urban N=2,570	All rural N=1,495	Large rural N=590	Small rural N=603	Isolated small rural N=302
Hospice program	**65.7%**	**61.8%**	65.6%	59.7%	58.6%
Palliative care program	**67.0%**	**40.8%**	49.7%	35.2%	34.8%
Inpatient palliative care unit	**25.2%**	**12.6%**	13.6%	11.3%	13.6%
Any PC[d]	**75.9%**	**69.1%**	72.7%	66.5%	67.2%

Data source: 2020 American Hospital Association Annual Survey.
Comparisons of urban and "all rural" categories were significant at P<.05 for all analyses.
[a]Includes services provided in the hospital, health system, or a joint venture owned or provided by the hospital or its subsidiary, provided by the hospital's health system in the local community, or provided through a formal contractual arrangement or joint venture with another provider in the local community.
[b]Excludes 2,028 nonrespondents to this section of the AHA survey. Missing: 1,391 urban hospitals (35.2% of total urban hospitals), 228 (27.9%) large rural; 244 (28.8%) small rural; 165 (35.3%) isolated rural.
[c]Rural-urban designations are based on Rural-Urban Commuting Area (RUCA) codes.
[d]Includes any hospital responding "yes" to at least one type of service (hospice program, palliative care services, or inpatient palliative care unit).