Rural Community-Based Palliative Care
Final Report

This report is part of an evaluation of the Rural Community-Based Palliative Care Project funded by Stratis Health. The NORC Walsh Center for Rural Health Analysis is conducting the evaluation, which will highlight efforts to develop and implement community-based palliative care in rural areas across three states: Washington, North Dakota, and Wisconsin. This report highlights key findings from NORC's mixed-method evaluation.

The Walsh Center
for Rural Health Analysis
NORC AT THE UNIVERSITY OF CHICAGO

The Walsh Center's mission is to conduct timely policy analyses and research that address the needs of government policymakers, providers, and the public on issues that affect health care and public health in rural America. The Walsh Center is part of the Public Health Research Department at NORC at the University of Chicago, and its offices are located in Bethesda, Maryland. The Center is named in honor of William B. Walsh, MD, whose lifelong mission was to bring health care to underserved and hard-to-reach populations. For more information about the Walsh Center and its publications, please contact:

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Executive Summary

Access to community-based palliative care services in rural areas often lags behind urban areas. To help address this gap in services, Stratis Health, supported by a grant from a philanthropic organization, provided funding and technical assistance to three states to support community-based palliative care implementation efforts in rural communities. State Offices of Rural Health (SORHs) in Washington, North Dakota, and Wisconsin supported several rural communities as they developed and implemented palliative care programs.

Methodology

To better understand the impact of the new community-based palliative care programs, NORC designed and conducted a mixed-methods outcome evaluation. The mixed-methods design integrated quantitative (i.e., program and survey data) and qualitative (e.g., site visit, phone interviews, document review) data collected over the course of two years. Descriptive statistics were used to analyze quantitative data, and thematic analysis was used for the qualitative data.

Lessons Learned and Policy Implications

Community-based palliative care programs face many of the same challenges as their urban counterparts, such as gaps in provider, patient, and community education about palliative care, as well as challenges related to reimbursement. Yet, rural communities are resilient and creative in their approaches to address these challenges by leveraging available resources to develop capacity to provide palliative care.

Conclusion

While research on palliative care has demonstrated benefits, less is known about community-based palliative care implementation in rural communities. This evaluation contributes to knowledge about the opportunities and challenges rural communities encounter in developing and sustaining palliative care programs, and elucidates that communities can re-imagine their collective capacity to make strides toward addressing an important gap in the continuum of care provided in rural areas.

Rural Community-Based Palliative Care Project Key Evaluation Findings

Patient Experience and Satisfaction

- Patients reported 1) satisfaction with the progress made towards reaching palliative care goals, 2) their palliative care team supports their main goals, and 3) their wishes were taken into account while receiving care from their team.
- Patients requested more assistance from their palliative care teams with cooking, physical therapy, and dietary education, among other topics.

Health Care Utilization

- When comparing the six months prior to enrollment to the first 60 days after enrollment, on average, emergency department visits, inpatient stays, and inpatient days decreased for participating patients.
- Programs were able to develop smoother transitions to hospice care for patients enrolled in palliative care programs compared to patients not enrolled.

Leadership and Workforce Development

- Champions of palliative care — individuals committed to improving access to palliative care in rural communities — facilitated the development and growth of the programs.
- Programs supported and encouraged staff members to earn certifications or trainings specific to hospice and palliative care medicine. Programs reported an increase in the number of staff with Palliative Care/Hospice Board Certifications and those participating in the End of Life Nursing Education Consortium (ELNEC).

Health Outcomes

- Patients reported improved symptom management in seven of nine core areas of health within the first month of enrolling in a palliative care program. Anxiety and nausea symptoms increased over the first 30 days across all reported programs.
- Pain, one of the key symptoms palliative care aims to alleviate, was one of the seven symptoms that lessened over the first month enrolled. Patients reported in surveys that their level of pain had affected their ability to enjoy life.

Team Composition

- Each palliative care team is inherently interdisciplinary to address the whole person's needs to achieve the goal of improved quality of life.
- Team composition and size varied depending on the maturity of the palliative care program. In addition to nurses and social workers, some teams also included pharmacists, massage therapists, and chaplains.

Introduction

The following introduction provides an overview of palliative care in the United States, including the background on its growth, its use in rural communities, barriers to implementing and expanding palliative care, and caregivers' involvement with care. This context is important to understanding the impetus for a new initiative developed by Stratis Health and evaluated by NORC, namely, the Stratis Health Rural Palliative Care Project.

Background on Palliative Care

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."[i] It includes providing relief from pain and other symptoms causing distress, neither hastening nor postponing death, and offering support systems to help patients live as actively as possible until death, among other things.[ii]

Palliative care in the United States evolved when hospice care became more accessible, particularly after the Medicare Hospice Benefit was approved by Congress in 1982 as part of the Tax Equity and Fiscal Responsibility Act.[iii] Given that hospice care was primarily provided in the patient's home during the last phase of life,[1] health care practitioners identified the need for a new type of care for cancer patients still receiving curative care who were not eligible or ready to transition to hospice care, particularly for pain management. As a result, in 1982 the Cancer Unit of WHO developed guidelines for cancer pain relief under the umbrella name *palliative care.*[iv] The health care system implemented palliative care both through the existing hospice care system and incorporated it into inpatient hospital care settings.[v]

As palliative care was provided primarily in the hospital and hospice care was provided in patients' homes, gaps in care became evident. Two key gaps were identified: 1) palliative care for patients with advanced illnesses who were not ready to elect hospice care, and 2) culturally appropriate palliative care. In an attempt to address the first gap, existing palliative care programs expanded outreach to these patients and streamlined care across various locations, particularly in communities. Exhibit 1 outlines current models of community-based palliative care programs, with specific programs highlighted.

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[1]Medicare and most health insurance providers require physician documentation noting that the patient is in their last six months of life before covering hospice care.

Exhibit 1. Existing Community-Based Palliative Care Program Models

Model	Description
Regional Delivery Model[vi]	A single facility consolidates the administrative functions of numerous satellite sites serving a large rural service area.
Medicaid Managed Care Integration[vii]	Palliative care integrated with Medicaid managed care organization.
C.P.C. Model[viii]	Outlines effective community-based palliative care practices: Consistent across transitions, Prognosis-independent, and Collaborative and coordinated (C.P.C.). Example: Project ENABLE
Community-Based Pediatric Palliative Care Model[ix]	Uses state-employed care coordinators to identify and enroll children with life-limiting illnesses who are eligible for the program. Independent hospice programs provide care to patients and families in the home from the point of diagnosis onwards. Example: Florida HCBS Waiver

Ongoing efforts to address palliative care gaps include providing culturally appropriate palliative care tailored to address communities' unique cultural needs, and increasing inter-professional educational opportunities for multi-disciplinary health care teams regarding the continuum of end-of-life care.[x] Expanding these efforts in rural communities increases access to high-quality palliative care for rural residents.

Today, palliative care is generally provided under three delivery models in the United States: 1) hospital palliative care, 2) community palliative care, and 3) hospice care.[xi] Research has established the potential benefits of palliative care across settings, as highlighted below, for both patients and their caregivers.

Proven Benefits of Palliative Care

Increased emotional support for patient compared to hospital or nursing home end-of-life care[xii]

More appropriate timing of transition to hospice care, with patients receiving hospice care for longer periods of time than expected from patients with usual care[xiii,xiv]

Increased patients' reported quality of life and symptom management when program focused on physical, psychosocial, and care coordination efforts[xv]

Improved symptom management, including depression[xvi,xvii]

Increased patient satisfaction with care received[xviii,xix]

Increased family and caregiver support, including higher self-efficacy for caring for their family member, better at addressing their own spiritual beliefs, and referral to psychosocial support[xx]

Caregiver Experiences

An estimated 40 million people in the U.S. provide unpaid care to an adult age 50 years or older.[xxi] Family caregivers report both their mental and physical health declining as a result of caring for their loved ones, including the development of depression and declining levels of overall physical health.[xxii,xxiii]

Researchers interviewed 73 family caregivers to better understand their experiences and the context for caring for a terminally ill relative. Two broad themes emerged from the interviews— family learnings/adaptations and family structure.[xxiv] The first theme included topics such as caregivers learning and adapting to holding different family roles, how to receive help or support themselves, researching and gathering information, and how to best honor the loved one's wishes.[xxv] It also identified that caregivers frequently wished to have better care for the ill relative, such as a physician recommending hospice care. The second theme uncovered both biopsychosocial and developmental factors of the family make-up, such as differences among geographic and environmental challenges faced (especially when needing to move the ill relative), generational differences among caregivers and the ill relative, and how specific events could act as triggers for reflections on life.[xxvi]

In Washington, the Palliative Care Initiative is a partnership between Western Washington University, Northwest Life Passages Coalition, and several nonprofit community organizations, aiming to transform palliative and end-of-life care in Whatcom County in western Washington state.[xxvii,xxviii] At its 2014 Summer Institute, 100 caregivers participated in discussion groups to discuss experiences within the palliative care system. The discussions were qualitatively assessed, and the overarching findings reported difficulties in interactions between both caregivers and patients with health care providers, caregivers feeling a lack of control over the schedules of personal care staff, and the impact of local culture on the challenge to develop palliative care services. The researchers noted that social workers should be proactive in fostering effective communication and trust between care providers and caregivers, and health care providers would benefit from communication training with patients and families.[xxix]

Barriers to Palliative Care Integration

As of 2012, there were approximately 1,700 hospitals with 50 or more beds with palliative care teams, serving about six million patients.[xxx,xxxi] Yet, about 90 million U.S. citizens live with a serious illness, and nearly 20 percent of Medicare beneficiaries have five or more chronic conditions,[xxxii,xxxiii] indicating a potential gap in palliative care service provision. In 2016, researchers conducted a literature review to identify the key *barriers to the integration* of palliative care services in the U.S. The following three overarching themes were identified:[xxxiv]

Exhibit 2. Barriers to Palliative Care Integration

Barrier	Description
Education	o Lack of adequate education and training for medical residents o Health care providers and the general public perceived palliative care as end-of-life care
Implementation	o Inadequate size of palliative care trained workforce o Challenge identifying patients appropriate for palliative care referral o Need for culture change regarding palliative care across settings
Policy	o Fragmented U.S. health care system o Need for greater funding for palliative care research o Lack of adequate reimbursement and incentives for palliative care for complex patients o Regulatory barriers to greater integration of palliative care in nursing homes

Barriers to Rural Palliative Care

For rural communities, the barriers to palliative care may be exacerbated by health system challenges faced by many rural areas, such as access to care. In 2016, the American Academy of Hospice and Palliative Medicine collaborated with researchers at George Washington University to profile the number of hospice and palliative care providers in the U.S. Research findings indicated there were 6,400 physicians who reported they were either board certified in hospice or palliative care or reported that their first or second subspecialty was hospice or palliative care, which resulted in 15.7 physicians per 100,000 individuals age 65 years and older.[xxxv] However, there is variation in access to palliative care physicians across the country, with high concentrations on the East and West coasts, and fewer physicians in the Midwest and South regions.[xxxvi] Even in areas with high concentrations of palliative care trained physicians, physicians were more often located near training sites (i.e., academic medical centers and children's hospitals) than in rural communities.[xxxvii]

Some rural palliative care programs have integrated technology to improve access to patients in their homes. Specifically, telemedicine and telemonitoring have increased access to timely care for rural palliative care practices.[xxxviii,xxxix] Although they are not recommended to fully replace home visits, these technologies allow for timely assessments and recommendations to manage patients' needs. In addition, because home visits take longer for nurses to conduct given the drive time between homes (i.e., windshield time), tele-visits permit for more impactful home visits to occur by freeing up the time it would have otherwise taken to conduct an in-home visit.

The demand for palliative care across the country – in both rural and urban areas – will continue to grow as the population ages and health care advances to extend one's life with chronic conditions. Yet, research predicts shortages in trained hospice and palliative medicine providers. One study predicts that by the year 2040, the U.S. will *require* between 10,640 and 24,000-trained providers to care for patients requesting hospice and palliative care medicine, while the *supply* of these providers will be around 8,100 to 19,000, depending on geographic areas.[xl] Rural areas are predicted to experience the greatest shortages. To help address these shortages, Stratis Health established the Rural Community-Based Palliative Care Project that

supports rural communities implement palliative care programs tailored for rural community teams that increases access to palliative care services for rural patients and caregivers.

Rural Community-Based Palliative Care Project

The goal of the Stratis Health Rural Community-Based Palliative Care Project is to develop, expand, and support rural communities committed to implementing a community-based palliative care program. Leveraging philanthropic grant funding, Stratis Health provided financial and technical assistance to three State Offices of Rural Health (SORHs) that, in turn, supported the implementation of palliative care programs in a cohort of rural communities. The three states selected for this project were Washington, North Dakota, and Wisconsin. The project used a staggered implementation, with Washington onboarding communities first, followed by North Dakota, then Wisconsin. The SORHs selected between six and nine communities to participate in the project. Communities were selected based on the following criteria: community interest, capacity to implement, and opportunity for learning about rural implementation. Each SORH provided technical assistance, support, and facilitated peer learning among communities.

Stratis Health engaged NORC to conduct an outcome evaluation of the Rural Community-Based Palliative Care Project, while Stratis Health focused on a process evaluation. The outcome evaluation aimed to not only assess the effects of the palliative care programs on the health and experiences of patients, caregivers, and providers, but also to support communities as they built their own capacity to offer palliative care. The following report describes the design of the evaluation, findings across select programs, and lessons learned that may be used to help inform or enhance existing palliative care efforts in rural communities.

Evaluation Design

The NORC team designed a mixed-methods outcome evaluation to assess the impact of the new palliative care programs on patients, caregivers, providers, and community stakeholders. Specific research questions developed to facilitate this assessment are highlighted in Exhibit 3 below, as well as primary and secondary data sources proposed to help answer those questions. Data were collected from rural palliative care programs from January 2019 through September 2020.

Methods

Data Collection and Retrieval

The mixed-methods design integrated quantitative (i.e., program and survey data) and qualitative (e.g., site visit, phone interviews, and document review) data collected over the course of two years. The NORC Institutional Review Board approved all aspects of primary data collection for the outcome evaluation. NORC collaborated with Stratis Health to carry out some aspects of primary data collection as described below.

Primary Data

- **Site visits:** NORC conducted in-person site visits with two communities in Washington and virtual site visits with two communities in North Dakota. Visits to both states included individual and group interviews with health care administrators and program leaders and staff to better understand the implementation experiences, successes, and challenges of each community. In-person visits in North Dakota were not possible due to the coronavirus pandemic and, instead, a series of phone calls or Zoom meetings facilitated qualitative data collection. In addition, the team spoke with the program lead for one coalition of participating counties in Wisconsin.
- **Interviews with state leads:** We conducted interviews with state leads from Washington, North Dakota, and Wisconsin. These interviews focused on how the state became involved in the Stratis Health Rural Community-Based Palliative Care Project, how they worked with and supported communities as they implemented their programs, and plans for continued involvement with rural palliative care in their state.
- **NORC developed two surveys to capture information from patients and caregivers about their experiences with the palliative care programs.** Survey items were primarily drawn from existing questionnaires used in palliative care, quality of life research, and health care. Surveys were distributed by mail or in-person to participating patients and caregivers along with a self-addressed stamped envelope for return directly to Stratis Health to encourage candid response from participants (programs would not see how they responded).

Secondary Data

- **Grantee program data:** Each quarter, communities were asked to update an Excel data collection workbook with patient metrics. These metrics included categories such as patient demographics, updated Edmonton Symptom Assessment System (ESAS) results conducted at follow-up visits, and health care utilization changes. The patient level data did not contain patient identifiers -- pseudo-identifiers were use. Communities uploaded their completed data collection workbooks to a Secure File Transfer Protocol (SFTP) site hosted by NORC.
- **Grantee needs assessment:** Communities completed a needs assessment at the beginning of their implementation phase and at the end of the project.

Exhibit 3. Rural Palliative Care Outcome Measures

Data Source	Secondary Data Sources		Primary Data Sources			
Common Evaluation Elements and Research Questions	**Grantee Program Data**	**Grantee Needs Assessment**	**Consultation with Project Officers**	**Caregiver Survey**	**Site Visits**	**Patient Survey**
1. Patient Experience/Satisfaction						
In what ways have patient and family satisfaction with care changed				✓	✓	✓
To what extent does the intervention affect measures of patient activation					✓	**PAM**
How have the programs affected caregiver burden				✓	✓	
To what extent have patients' self-directed goals been met				✓	✓	✓
2. Utilization						
To what extent have rates of hospitalization and re-hospitalization changed	✓			✓		✓
To what extent have levels of emergency department utilization changed	✓			✓		✓
To what extent has intensity of inpatient utilization changed	✓			✓		✓
3. Community Capacity/Capability						
To what extent have sustainable multidisciplinary/multi-settings teams been established in each cohort		✓	✓		✓	
How well have the lead organizations in each community coordinated project activities		✓	✓		✓	
To what extent do communities have adequately trained professionals to staff the programs	✓	✓	✓		✓	
Have the communities achieved their own stated goals	✓	✓	✓		✓	

Data Source	Secondary Data Sources		Primary Data Sources			
Common Evaluation Elements and Research Questions	**Grantee Program Data**	**Grantee Needs Assessment**	**Consultation with Project Officers**	**Caregiver Survey**	**Site Visits**	**Patient Survey**
4. Health Outcomes						
To what extent do the interventions improve quality of life	✓			✓	✓	**ESAS**
To what extent do the programs help patients manage pain symptoms	✓			✓	✓	**ESAS**
To what extent do the programs address depression and loneliness in patients	✓			✓	✓	**ESAS/3-Item Loneliness Scale**
5. Provider Outcomes						
To what extent are providers satisfied with the care they are providing			✓		✓	
To what extent do providers feel prepared to provide palliative care in the community			✓		✓	
In what ways are providers working across disciplines to provide care			✓		✓	
To what extent have provider palliative care skills and knowledge changed			✓		✓	

Notes: ESAS = Edmonton Symptom Assessment Scale. PAM = Patient Activation Measure.

Analysis

Prior to analysis, the NORC team assessed the feasibility of using the grantee program data to answer the evaluation's research questions. Data collected from rural populations is often limited in quantity given the sparsely populated rural communities. This often results in small cell sizes (i.e., less than 11) for any given variable of interest. Small cell sizes increase the possibility that the identity of the individuals may be identified. To protect the confidentiality of patients, small cell sizes are suppressed when reporting results and/or combined with other data to reduce the likelihood of re-identification of patients.

Small cell sizes were identified in the data from the Rural Community-Based Palliative Care Project. By late fall of 2020, we had received program data on 108 patients across three program sites in Washington and North Dakota.

When reviewing program data by program and by state, we identified several metrics with small cell sizes -- source of referral to palliative care consultation, patient age, and primary reason for consultation. The small cell sizes would have limited our reporting of quantitative findings if reported by site, so all data were combined. The combined dataset facilitated a more robust assessment of the impact of rural community-based palliative care programs while protecting patient and caregiver confidentiality.

By late fall of 2020, 10 patients and 11 caregivers from across all programs in both states had submitted surveys. To protect respondents' confidentiality, we have not reported tabulations of their responses in this report. Where possible, we reference high-level findings from the surveys without tallying any responses or referencing the program in which the patient or caregiver participated.

Once combined, program and survey data were analyzed using descriptive statistics and organized around the evaluation elements noted in Exhibit 3. SAS v.9.4 was used for data analysis. We analyzed ESAS and health care utilization only for patients whose data were reported twice (i.e., pre-post analysis was conducted).

Qualitative data collected during in-person site visits, virtual site visits, and individual or group interviews were analyzed for common themes and summarized in state-level reports (see Appendices C-E). These data are available for four communities, two each in Washington and North Dakota. Document review entailed a review of results from a pre- and post-asset and gap analysis conducted at two points over the course of the Rural Community-Based Palliative Care Project.

Limitations of the Evaluation

When we developed research questions for this evaluation, we anticipated that most communities participating in the Rural Community-Based Palliative Care Project would collect data. We aimed to analyze program and survey data collected between January 2019 and September 2020 by state and by program. However, not all communities participating in the

Rural Community-Based Palliative Care Project collected program data or facilitated survey administration to patients and caregivers. For some communities, the staggered nature of the project rollout meant that they had not reached a level of implementation in which data collection for the evaluation would be meaningful or possible within the evaluation timeframe (e.g., one community in North Dakota joined the project less than one year before the data collection period ended). Other communities were uncertain about the appropriateness of established evaluation metrics for their palliative care programs. In addition, the coronavirus pandemic affected program priorities, and data collection was understandably de-prioritized. These factors collectively affected the size of the analytic samples by program and by state.

The influence of the palliative care programs on health care utilization and cost using claims data was not included in this analysis. Claims data often lag at least 18 months and given the timeframe and resources for the evaluation, these data were not included in the analysis.

Another limitation unique to this evaluation was the impact of the coronavirus pandemic on the NORC team's ability to conduct site visits in person. Plans to visit two North Dakota communities in the spring of 2020 were canceled due to travel restrictions. While the NORC team was able to connect via Zoom and phone with the communities, including interviews with several palliative care team members, the opportunity for important in-person observations (e.g., interpersonal interactions between team members) was not possible.

Findings

Each palliative care program is administered by a critical access hospital (CAH) and integrated into the hospital's array of service offerings. Dedicated and passionate palliative care champions in rural communities lead and coordinate staff to design and implement the programs. These leaders, supported by multidisciplinary teams, recognize the need for palliative care services and are committed to overcoming obstacles in order to make their visions a reality. The palliative care programs leveraged existing hospital and community-based services to coordinate and, where appropriate, tailor those services for patients and caregivers around the guiding philosophy of palliative care that focuses on the "…assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." Exhibit 4 illustrates the most common structure of rural community palliative care programs participating in this project.

Exhibit 4. Example of Rural Community Palliative Care Program Structure
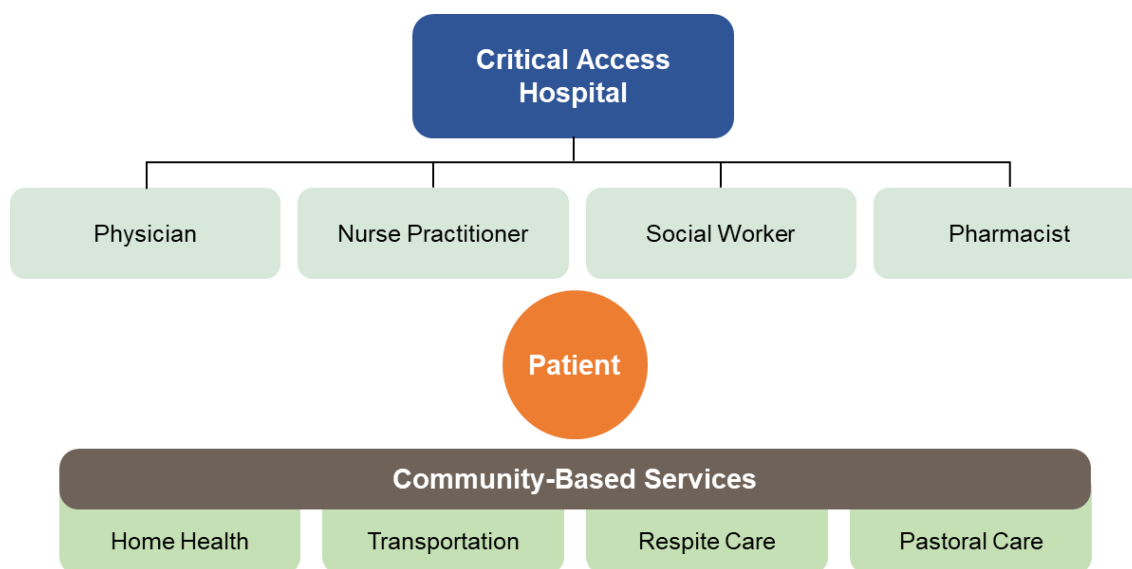
The following sections present a summary of findings from site visits, program data, document review, and select survey responses. We present patient characteristics and evaluation findings, which are organized around the research domains outlined in Exhibit 3.

Exhibit 5 summarizes the patients participating in the program. Nearly 70 percent (n=75) of patients were 65 years old or older, while 23 percent (n=25) were 85 years old or older. Most patients (82 percent; n=89) were living at home when they enrolled in palliative care. Program staff described a range of living arrangements, with some patients living alone and some living with family.

The extent to which the palliative care program also supported family caregivers may affect patient and caregiver experiences. For example, all but one caregiver who responded to the survey reported that they were either satisfied or very satisfied with the availability of the

palliative care team to the family. Similar findings were reported for caregivers' satisfaction with emotional support the palliative care program provided to family members.

Exhibit 5. Patient Characteristics

Total Patients: 108

Patient Age at initial consult (years)
Under 65: 33 (31%)
65-84: 50 (46%)
85 and older: 25 (23%)

Discharge Status from Program
Died: 25 (23%)
Transitioned to hospice: 14 (13%)
Patient declined further services: 12 (11%)
Goals of palliative care were met: 10 (9%)
Other: 11 (10%)
Not discharged/Not reported: 36 (33%)

Patient Residence at Initial Consult
Home/apartment: 89 (82%)
Nursing home/assisted living/senior housing: 14 (13%)
Other: 5 (5%)

Notes: Data compiled from three programs (two in Washington, one in North Dakota).

Patient Experience and Satisfaction

The patient experience survey was the main data source to examine research questions pertaining to patient experience and satisfaction with the palliative care program. Due to the low number of survey respondents, some of the findings are suppressed to maintain patient confidentiality, while other results are described at a high-level or taken from open-ended responses to provide an enhanced context about patient satisfaction and experience with the program.

Overall, the majority of patients agreed or strongly agreed with the following statements asked in the survey:

- I am satisfied with the progress I have made to reach my main goal.
- My palliative care program supports the main goal I made at enrollment.
- My palliative care program takes my wishes into account when providing care to me.

The patient survey also included a free-form question asking patients, "What's the one thing that you wish your palliative care program could be more helpful with?" Patients provided the following responses:

- Assist with cooking
- Complete lab draws and other testing
- Provide physical therapy

- Include dietary education

Each site team interviewed recognized the role that palliative care plays in providing wraparound services to address the multifaceted needs of patients. Those needs often include traditional community-based services such as transportation or Meals on Wheels, but also more non-traditional services such as massage therapy. The programs' commitment to providing a unique patient experience that is tailored to the needs of each patient likely plays a key role in patient satisfaction.

Washington State's Rural Palliative Care Initiative Handbook (Appendix B)

The Washington Rural Palliative Care Initiative Handbook

July 2020

Washington State Department of
Health

During our site visit to Washington, we also learned how programs could enhance the lives of caregivers. We spoke with two caregivers during the site visit, and both expressed their gratitude for the program and the care provided to their loved ones. One caregiver described how the team provided information about the program and explained the difference between hospice and palliative care, and helped her to understand what was happening with her husband's condition. The caregiver noted that she was "relieved to have someone else involved."

Providers shared stories of patients or caregivers who showed their appreciation, such as sending personal notes and cards, which affirmed the providers' roles in providing essential patient care through palliative care services.

> *The palliative care team checked in with the caregiver in the emergency department when her husband needed care, and the "friendly face" helped reduce the caregiver's stress during that time.*

Health Care Utilization

As part of the program data collection, program staffs were requested to conduct a medical record review of their palliative care patients to count the number of emergency department (ED) visits, inpatient (IP) stays, and IP days. The review was conducted over two time periods — the six months leading up to the patient enrolling in palliative care (six-month lookback) and the first 60 days after enrolling. Exhibit 6 presents the average number of ED visits, IP stays, and IP days for both time periods across all programs that submitted program data.

Exhibit 6. Average Change in Health Care Utilization for Palliative Care Patients
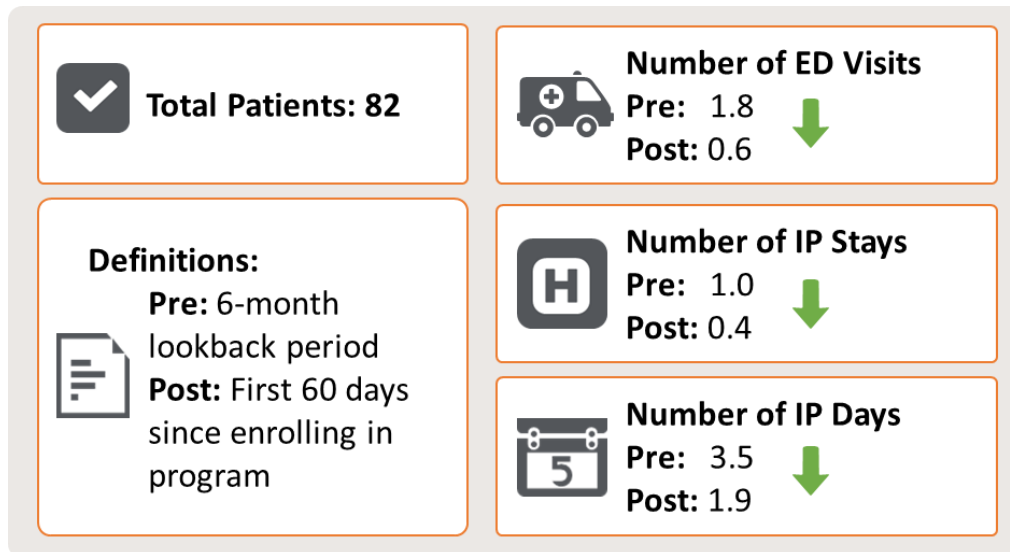
Note: ↓ indicates a decrease in the average utilization. This analysis included 82 patients for whom documentation of health care utilization was reported for both time periods analyzed.

Overall, health care utilization decreased across the three measures analyzed. While ED visits decreased an average of 1.2 visits, IP stays decreased by 0.6 stays and IP days decreased by 1.6 days. Similar utilization questions were asked in the patient survey regarding the change in frequency they visited the ED, were admitted to the hospital, and the length of these admissions (if occurred) since enrolling in palliative care. Survey respondents indicated their use had remained the same as before starting the program or had decreased in the two-months since starting the program. One potential limitation is the difference in length of time used for the comparison. The record review lookback period covered six months; however, the patient's timeframe was two months post-enrollment.

Program staff reported that rural palliative care utilization resulted in timely hospice enrollment. Two North Dakota programs observed a noticeably smoother transition to hospice care for patients already participating in palliative care than for patients who were not enrolled in palliative care. In particular, patients were less hesitant to begin hospice care if they were familiar with hospice staff, many of whom also provided palliative care. The overlap between the two teams—palliative care and hospice—helped patients feel more comfortable and less apprehensive about hospice care.

Community Capacity and Capability

Programs engaged interdisciplinary teams of providers comprised of physicians, physician assistants, nurse practitioners, nurses, pharmacists, community health workers, clergy, and social workers. Each program reported the composition of their team and services offered at the beginning and end of the rural palliative care project via an asset and gap analysis. The asset and gap survey data were collected: (pre) just prior to an initial project workshop (sponsored by Stratis Health) and (post) approximately six to nine months after the initial workshop. While

program team composition and services remained the same for many programs during the course of the project, changes also occurred as programs evolved. For example, one program added bereavement care, community health workers, and support group services, while discontinuing home health services. Another program reported adding respite care services. More details on program composition for three communities reporting pre- and post-asset and gap surveys are shown in Exhibit 7.

Exhibit 7. Program Composition Before and After Project

Indicate which services are currently provided directly by an organization represented on your Community Team.	Community A		Community B		Community C	
	Pre	Post	Pre	Post	Pre	Post
Adult/geriatric nurse practitioner	■	■			■	■
Bereavement care (apart from hospice)		■			■	■
Case management for chronic disease	■	■	■	■	■	■
Community health workers		■	■	■		
Home care (supportive care)	■	■	■	■		
Home health services (medical care)	■		■	■	■	■
Hospice care	■	■	■	■	■	■
Medical social worker	■	■	■	■	■	■
Pain management consultation	■	■				
Parish nursing						
Pastoral care/chaplaincy	■	■	■	■	■	■
Respite care for family caregivers apart from hospice	■	■		■	■	■
Support groups, such as caregiver support groups or grief support groups		■	■	■	■	■
Transportation	■	■	■	■		

Source: Asset and Gap Analysis Results, Stratis Health.

Washington Community on Leadership: *"You've got to have a personality that can be flexible... If you're rigid and you need to do it certain ways… you're going to struggle. But I don't think most rural communities have those types of personalities. They have independent people, but they have had to do things differently to make it work and it usually involves a team of people; they don't usually do it alone."*

Each community identified a palliative care champion – an individual committed to improving access to palliative care who facilitated the establishment and growth of the program. While there was *some* turnover among champions, most continued moving their programs forward.

The CAHs that facilitated new palliative care programs have aimed to create supportive environments that embrace the use of palliative care. The whole-person approach to palliative care requires coordination of services among different disciplines in order to maximize the impact of the care provided by the team. By establishing palliative care programs, the CAHs have helped to fill an important gap in providing enhanced care coordination.

One of the greatest challenges identified by program implementers is educating providers who are not part of the palliative care team. Buy-in from these providers facilitates palliative care enrollment to ensure patients receive appropriate, whole-person care from all providers. The need for more provider education was noted by new and established palliative care programs. In Wisconsin, where the focus of the Rural Community-Based Palliative Care Project was provider and community education at existing palliative care organizations or health systems, lead "coalitions" sought to use a cache of PowerPoint presentations and handouts (see snapshot below) to improve understanding of palliative care for different audiences. While the coronavirus pandemic may have slowed down efforts to provide education among the community (given social distancing requirements) and providers (given shifting health care priorities), these materials will be ready for use when the pandemic ends.

Wisconsin Palliative Care One-Pager (Appendix C)
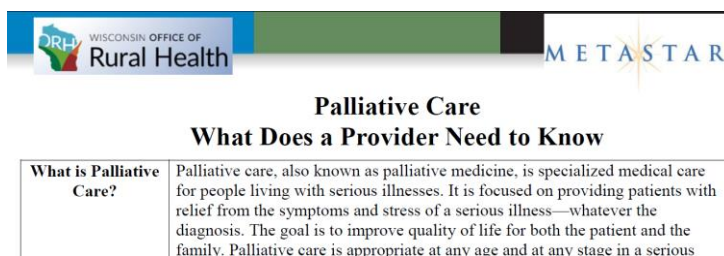
Program Staff Training

As part of the asset and gap analysis that Stratis Health conducted with the program teams, the programs were asked to count the number of staff who earned certifications or trainings related to hospice and palliative care medicine. Certifications and training in hospice and palliative care were reported in the pre and post surveys for the following program staff: chaplains; nurse assistants, nurses, and nurse practitioners; physicians and physician assistants; pharmacists; social workers; and other staff.

Exhibit 8 includes the number of program staff who completed hospice and/or palliative care certification/training as reported in the pre and post asset and gap surveys.

Exhibit 8. Number of Program Staff Who Completed Hospice and Palliative Care Certifications/Training as Reported in Pre and Post Asset and Gap Surveys

Certification/Training Name	Pre	Post
Palliative Care/Hospice Board Certification (Physicians and nurses)	5	6
Education in Palliative and End of Life Care (EPEC) (Physicians)	2	2
End of Life Nursing Education Consortium (ELNEC) (Nurses)	17	23
Other Palliative Care/Hospice Training or Education (e.g., Palliative Care Leadership Center or clinical training)	22	22

Source: Asset and Gap Analysis Results, Stratis Health.

The number of staff with board certifications and ELNEC both increased over the time period analyzed, while EPEC and other trainings remained stable over time. The increase in training reported in the asset and gap analysis was supported by site visit findings. All programs

described that at least some of their team members had received training in palliative care, though the amount of training, source, and content varied. At least one community cited the need for additional training.

Program Goals

In the asset and gap analysis, Stratis Health asked a series of three questions to participating communities regarding their goals for the program. In the pre-asset and gap survey, communities were asked to list the "three most important things you want to accomplish with this project." In the post-asset and gap analysis, communities were asked to list the "three most important things your team accomplished with this project" and the "top three things your team is still working towards." The responses for the three communities that also submitted program data are summarized in Exhibit 9.

Exhibit 9. Goal Setting and Attainment Status of Community Programs

Question	Reponses
Initial: Want to accomplish	▪ Palliative care education on consultation and timing of referrals for health care community and program staff, community partners, patients and family ▪ Improve care coordination, well-trained consultation team, and establish formal referral processes ▪ Fully implement palliative care program ▪ Improve patient satisfaction ▪ Develop data analytics capacity ▪ Establish reimbursement mechanisms for the palliative care consultation
Follow-up: Accomplished	▪ Implemented a palliative care program, developed outpatient services, transitioned to telehealth services ▪ Helped patients and families meet their care goals, improved patients' quality of life ▪ Increased knowledge of chronic condition symptom and disease management ▪ Became a leader of providing palliative care services to rural communities in the state ▪ Increased the length of hospice care utilized
Follow-up: Still working towards	▪ Community outreach and education ▪ Increase program utilization and implement standardized telehealth services ▪ Increase staff trained in palliative care certifications; spiritual care ▪ Increase full-time staff members and gain provider "buy-in" of program

At the outset, programs focused their goals on some of the common barriers to palliative care, including stakeholder (e.g., staff, provider, patient, and community) education and reimbursement. Programs reported success with education efforts in their follow-up asset and gap analysis and during site visit interviews. While programs were repeatedly challenged by the education gap, they were making strides to address it.

Programs also reported implementation successes, and program data indicated increases in utilization. However, securing reimbursement for palliative care services may be more difficult to achieve in the short-term, given the relatively slow pace of policy change. Interim goals, such as informing local legislators about the need for palliative care funding during the next state

legislative session, may be helpful to begin the dialogue for states to require coverage of some palliative care services through Medicaid and commercial insurers.

Health Outcomes

Quality of Life and ESAS Survey Results

The main pillar of palliative care is to "promote[s] quality of life by addressing the physical, psychological, emotional, cultural, social, and spiritual needs of patients and families."[xli] One way to measure quality of life is to regularly document changes in the common symptoms related to a palliative care patient's serious illness. Since its inception in 1991, the Edmonton Symptom Assessment System, or ESAS, has been used to methodically measure patient symptoms, and overall quality of life, efficiently and in a way that is easy for patients to answer.[xlii]

As part of the Rural Community-Based Palliative Care Project, palliative care staff members were requested to conduct the ESAS survey for each patient at the initial visit, at the 30-day follow-up visit, and at the final visit. The survey used in this program included nine symptoms: pain, tiredness, well-being, depression, anxiety, drowsiness, nausea, shortness of breath, and lack of appetite.[2] Patients selected a number on a scale of 0–10 that best described their level of the specified symptom. The scale is measured with 0 being the lowest level of the symptom, while 10 indicates the highest level of the symptom. Thus, a decrease in an ESAS score over time indicates that the symptom has improved over that time period. The only exception is well-being, where the highest overall well-being is scored a 0 and worst is 10.

Across all programs that submitted program data, staff conducted the ESAS at both the initial and 30-day follow-up visit for 19 patients. To measure the change in patients' quality of life throughout the program, we calculated the average response across all nine metrics included for both time periods. Exhibit 10 presents the findings.

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[2] The survey also included the field "Other," but no write-in option was offered; this survey field was not included in the analysis since it was not interpretable.

Exhibit 10. ESAS Scores by Category: Initial vs. 30-Day Follow-up

	Initial	30-Day Follow-up	Change
Pain	5.3	4.5	▼
Tiredness	5.8	5.3	▼
Well-being	6.9	4.6	▼
Depression	5.0	4.8	▼
Anxiety	4.1	4.9	▲
Drowsiness	4.9	3.9	▼
Nausea	2.1	2.3	▲
Shortness of Breath	4.4	3.4	▼
Lack of Appetite	4.7	4.2	▼

Notes: Results are limited to the 19 patients who had both an initial and 30-day follow-up ESAS performed. ▲ indicates an increase in the average, i.e., a negative outcome; ▼ indicates a decrease in the average score, i.e., a positive outcome.

The results, albeit based on responses from a small number of patients (n=19), are promising. Between the initial and 30-day follow-up, patients reported an improvement (or a decrease in the average number) in seven of the nine symptoms assessed. Anxiety and nausea are the two symptoms that patients reported that the symptom slightly worsened, from an average score of 4.1 to 4.9 for anxiety and 2.1 to 2.3 for nausea.

Among the symptoms that improved, patients scored the greatest positive change in overall well-being, from an average score of 6.9 at the initial survey to an average score of 4.6 at the 30-day follow-up survey. In addition, patients reported that, on average, scores for pain decreased from 5.3 to 4.5 and depression decreased from 5.0 to 4.8, between the initial and 30-day follow-up scales administered. A series of questions in the patient survey asked about the severity of pain experienced over the last week and the extent to which pain affected the patient's ability to enjoy life. For the latter, all but one patient responded that some level of pain affected their ability to enjoy life, highlighting the importance of minimizing this symptom for palliative care patients.

Provider Outcomes

Each palliative care team is inherently interdisciplinary by design in order to achieve the goal of improved quality of life (the goal of palliative care[xliii]), which takes multiple facets of a person's life into account. The teams we interviewed were comprised of providers who could address the physical, social, emotional, and sometimes spiritual needs of patients, though team compositions differed. The palliative care teams in North Dakota, that had begun program implementation after those in Washington, were more limited in size than those in Washington.

Chaplain's Role

In one North Dakota community, the chaplain is a valued part of the team, and the team recognizes that spiritual care is important and would like to utilize it more. The chaplain conducts an initial visit with the patient once they are admitted to palliative care, then continues as the patient's pastor or facilitates a connection to the patient's regular pastor. The chaplain reflected on how he understands that palliative care patients are experiencing multiple stages of grief, and how patients feel challenged to reach their goals. This conversation highlighted the insightful nature of the pastor, a characteristic valued by his team members. As one provider quipped when asked for advice on implementing palliative care programs, spiritual and emotional needs are not "fixed with a pill."

In addition to typical palliative care providers, such as nurses and social workers, one team in Washington also included a pharmacist and massage therapist.

Regardless of team composition, providers were committed to making their palliative care programs a success. A clear indication of this commitment is their willingness to try to "squeeze in" their palliative care work around their regular and "billable" work. Juggling priorities creates stress for staff, as reported by one community in Washington. Some staff members also describe taking on multiple roles on their teams to ensure implementation moved forward. While "wearing many hats" may benefit the scope of work that can be accomplished, it also contributes to stress. During interviews with staff, they referred to the lack of time as a challenge.

Providers in all communities participated in palliative care training, though the extent of training and types of staff participating varied. In addition, both North Dakota communities stated that more training was necessary.

Lessons Learned and Policy Relevant Themes

A discussion of lessons learned and considerations for implementing palliative care in rural communities follows, including the role of policy to expand access to community-based palliative care in rural areas.

Improve community and provider education. One of the biggest barriers to program growth is the lack of understanding of palliative care on the part of patients, families, the community, and providers. The barrier manifests when patients and families mistake palliative care for hospice care, the latter of which they may avoid because of what it signifies (i.e., the end of life), and are consequently reluctant to use palliative care. This misunderstanding may mean lost opportunities for the patient to benefit from the whole-person care that a palliative care approach provides and the focus on enhanced quality of life during a serious illness -- something that may be overlooked when the attention remains solely on treatment.

North Dakota's Palliative Care Flyer (Appendix D)

Lack of education and understanding may also be a challenge for providers and staff, particularly as it relates to provider buy-in. Palliative care staff may find that coordinating or providing care to their patients is more difficult because other providers and staff do not value the palliative care approach for their patients. Increasing opportunities for providers and staff to attend regular interdisciplinary team meetings, where each palliative care team member discusses the patient's care from their own perspective and demonstrates the value of the multidisciplinary approach, may be one strategy for building support for palliative care. Although lack of understanding about palliative care among providers is not unique to rural areas, access to training for rural providers may be a distinguishing barrier. Advancements and provider acceptance of remote learning opportunities, such as Project ECHO, may help accelerate the implementation of rural community palliative care programs.

Maximize existing resources. Palliative care brings together providers that address the physical, psychosocial, and spiritual problems[xliv] of individuals living with a serious illness. The range of disciplines encompassed by palliative care includes physicians, nurses, and social workers,[xlv] as well as chaplains, pharmacists, and nutritionists.[xlvi] Inclusion of these disciplines, particularly in rural areas, may be limited by provider availability, or willingness of an available provider to participate on the palliative care team. For those seeking to develop palliative care in rural communities, as we learned from this project, the composition of the team need not be all-encompassing, or made up of new providers, or even comprised of providers already trained in palliative care. Most programs began with core members, such as a nurse practitioner, registered nurse, and social worker, and often rounded out their team with providers already

serving palliative care patients in other capacities (e.g., home health nurse or community health worker) who agreed to work with the palliative care team. Teams were also able to integrate chronic care management (CCM) services into their plans of care, allowing providers such as nurse practitioners to provide care according to the palliative care approach, and receive reimbursement under CCM.

While some team members brought experience and training in palliative care to the team, others did not, but were willing and enthusiastic about completing training. As mentioned previously, the amount of training that team members completed varied by member and program, but the common thread was a desire to learn more so they could do more. State policies that require providers to be educated about palliative care may result in increased access to palliative care services. For example, Vermont enacted legislation that requires physicians to complete at least one CME hour on "hospice, palliative care, or pain management services." [xlvii]

Plan for sustainability. While programs have found success implementing their palliative care programs using existing resources and providers, their ability to build capacity and expand their programs without overtaxing their staff rests on more sustainable and stable financial support. One potential reimbursement avenue identified during the pandemic was the use of telehealth in the patient's home, which became reimbursable under Medicare during the public health emergency and expanded to become a permanent benefit reimbursable under Medicare. [xlviii] For patients in rural areas who often lack access to transportation, traveling to a clinic is often a barrier to receiving care. Yet, access to telehealth in a patient's home may be a challenge due to poor broadband coverage, lack of technology (e.g., smart phones and tablets), and limited familiarity with using the technology. [xlix] However, some palliative care programs participating in this project successfully used remote care via telephone and Zoom with patients.

Reimbursement for palliative care services was noted as the greatest challenge to sustaining and expanding palliative care services. The extent to which private and public payers reimburse for palliative care services varies widely. Some states are paving the way for palliative care reimbursement through Medicaid, including California's managed care model (Medi-Cal), [l] while other states are pursing commercial insurance coverage. Although most patients in the programs participating in this project were Medicare beneficiaries, approximately one-third of patients were under 65 years of age. It may be possible for private insurance to cover some of the palliative care costs; however, reimbursement may be limited to pain management. [li] Policy changes directed at reimbursement among public payers may mitigate some of the challenges rural palliative care programs confront when trying to fund palliative care services on limited budgets.

Conclusion

The Stratis Health Rural Palliative Care Project supported rural community palliative care programs in three states – Washington, North Dakota and Wisconsin. The rural communities in Washington and North Dakota leveraged existing resources to design and implement palliative care programs while rural Wisconsin communities increased educational efforts for existing palliative care programs. NORC's Walsh Center for Rural Health Analysis employed a mixed-method evaluation to understand program facilitators and barriers to achieving goals. Although the coronavirus public health emergency affected some program implementation plans and evaluation activities, the project resulted in a number of new palliative care access points in rural communities and an increased understanding for providers and community members of how palliative care can enhance quality of life for patients and their caregivers.

A key facilitator for success in all three states was identifying a state palliative care expert and rural community palliative care champions. The state palliative care expert served as a subject matter expert, facilitated palliative care training opportunities, and convened the palliative care teams to share success and lessons learned. The rural community champion provided the local palliative care program with leadership and served as a connector to providers, patients, and community stakeholders. The importance of passionate, committed, and knowledgeable leaders cannot be understated – it is the "secret sauce" of successful rural palliative care programs. In contrast, rural communities that experienced high turnover of leadership and staff struggled to make progress toward their goals.

The primary barrier in expanding access to palliative care in rural communities is reimbursement. Although some programs leveraged Medicare's chronic care management payments to cover some of the costs of providing palliative care services, other programs noted that it was difficult to identify any reimbursement streams from Medicare, Medicaid and commercial payers. As rural providers continue to move to value-based payment and delivery models, such as accountable care organizations (ACOs) and capitated payments, there may be flexibility for rural providers to fund palliative care services. In addition, the coronavirus public health emergency also created new opportunities to use telehealth that may increase access to palliative care services for rural residents. Project participants noted they would continue to access Stratis Health's online Rural Palliative Care Resource Center for reimbursement and program implementation guidance post grant funding.

As palliative care programs evolve and new programs are implemented in rural communities, it is important to assess the local needs of the community while also evaluating the extent to which programs meet the needs of patients. For example, patients identified services, such as nutrition education and assistance with cooking, that they wished the palliative care program could provide. Programs noted that they greatly rely on staff's knowledge of the community so that unmet needs that cannot be provided by the palliative care team may be provided by other community organizations. Patients' suggestions for additional assistance may also help to guide expansion of palliative care services. Building assessment and evaluation capacity in rural communities is essential for sustaining programs, meeting patient and caregivers needs, and supporting rural health administrators in allocating resources most efficaciously.

Although the data were limited in the evaluation of the rural palliative care programs, promising trends emerged in health care utilization, including decreases in ED visits and hospitalizations following admission to palliative care. These utilization findings in addition to positive comments from patients and caregivers, and feedback from providers regarding their enthusiasm for the program, underscore that rural palliative care programs have built a solid foundation on which they can continue to expand and serve their rural communities.

Overall, grant funding was essential in supporting the three states' palliative care networks of rural community participants, including each state's palliative care expert, providing palliative care resources, and creating a forum to share lessons learned and best practices. As the number of older adults in rural communities continues to increase with the aging of the baby boomers, identifying effective rural community programs that support aging in place for patients and their caregivers will continue to be a priority. Palliative care serves as a glide path for patients, caregivers and health care providers when a patient's goal is to embrace comfort care and focus on quality-of-life during a serious or life-threatening illness. What could be more germane to rural communities than taking care of neighbors when they need it most?

Appendix A. Program Maps

Below are maps of the three states that participated in the Stratis Health Rural Community-Based Palliative Care Project, including their participating communities.

Throughout the evaluation, NORC collaborated with Cohort 1 in Washington State.
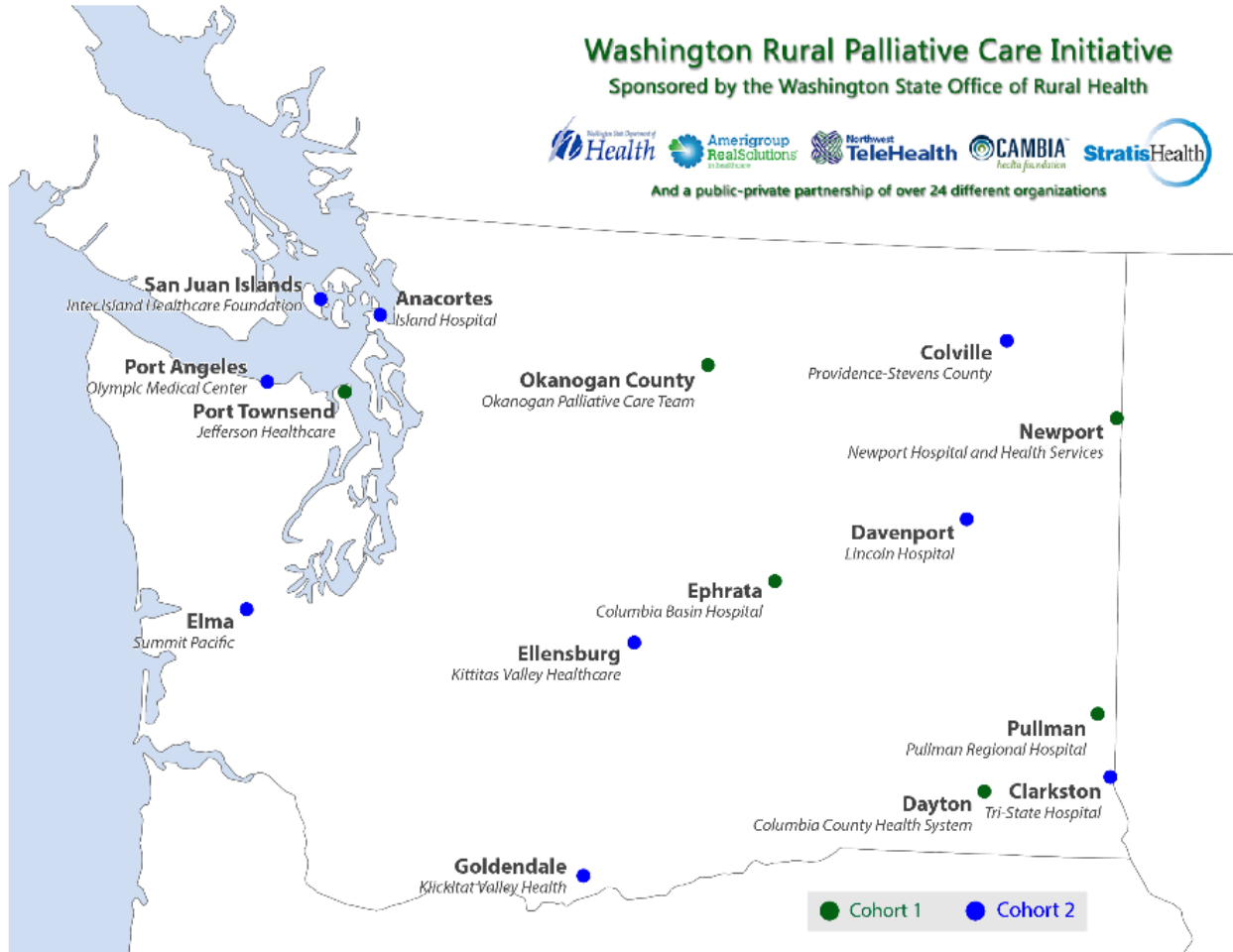
Source: Healthier Washington Collaboration Portal. Retrieved from:
https://waportal.org/partners/home/washington-rural-palliative-care-initiative

North Dakota Rural Community-Based Palliative Care Project
Participating Communities
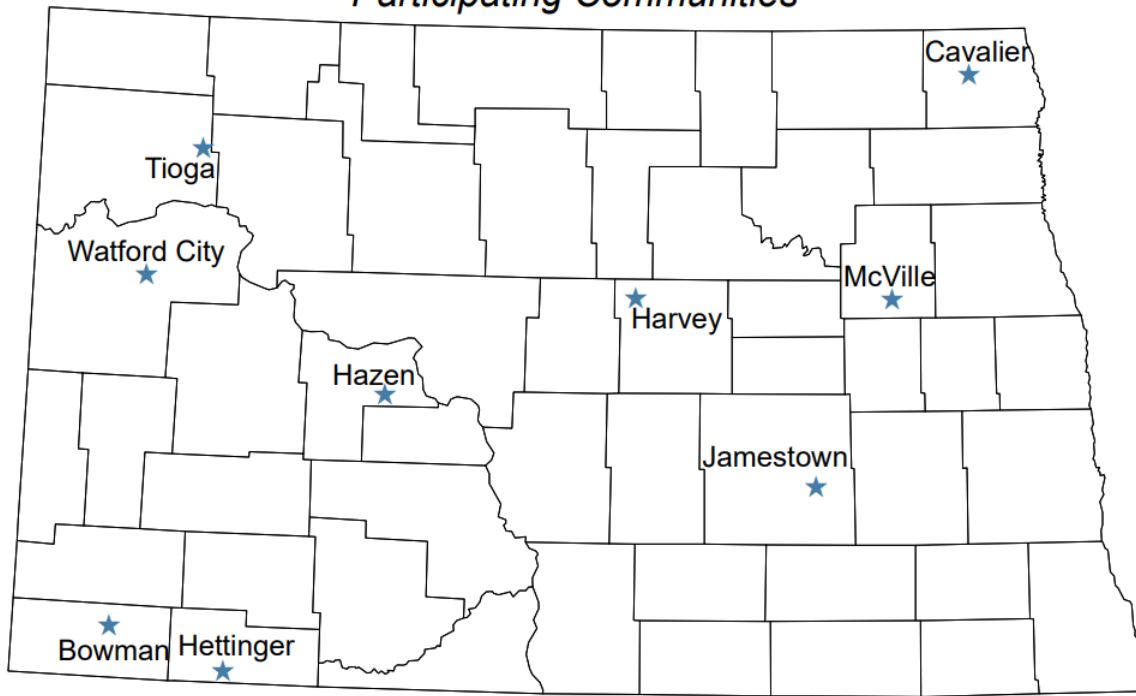
Source: North Dakota Rural Community-Based Palliative Care Project

Created by the North Dakota Healthcare Workforce Group on 4/2020

Retrieved from: https://ruralhealth.und.edu/files/maps/community-palliative-care-map.pdf

Wisconsin Rural Community-Based Palliative Care Coalitions
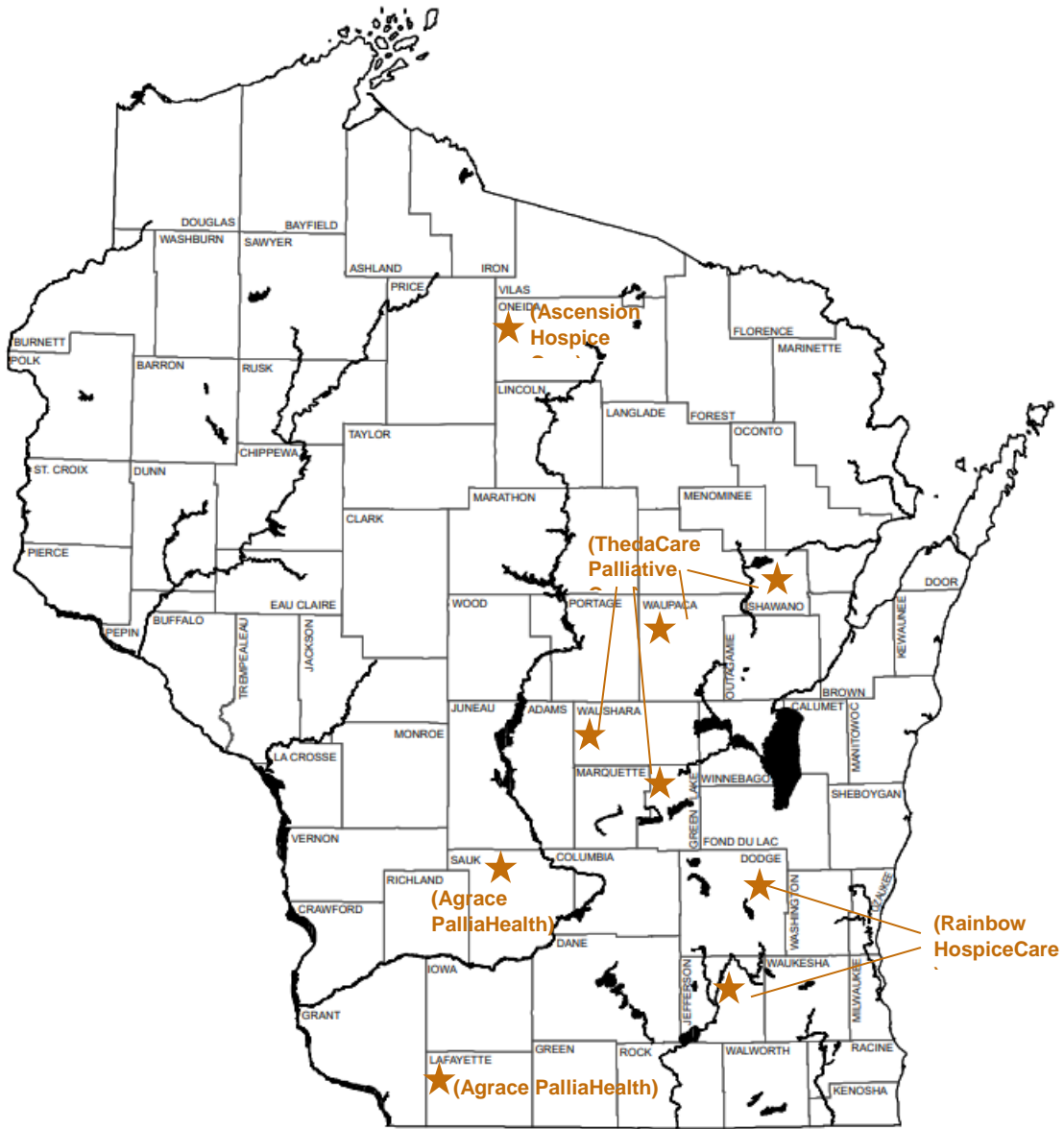
Notes: County and Coalition information retrieved from the Wisconsin Office of Rural Health website at:
http://worh.org/rural-community-based-palliative-care

Appendix B. The Washington Rural Palliative Care Initiative Handbook

Retrieved from: https://waportal.org/sites/default/files/2020-08/WRPCI%20Handbook-Final7-31-2020_1.pdf

Washington Rural Palliative Care Initiative

The **Washington Rural Palliative Care Initiative** (WRPCI) is an effort to better serve patients with serious illness in rural communities. Led by the Washington State Office of Rural Health at the Washington State Department of Health, this public-private partnership involves over 24 different organizations to assist rural health systems and communities to integrate palliative care in multiple settings, such as emergency department, inpatient, skilled rehabilitation, home health, hospice, primary care, and long-term care.

What is Palliative Care?

Palliative care is specialized care for people living with serious illness. Care is focused on relief from the symptoms and stress of the illness and treatment—whatever the diagnosis. The goal is to improve and sustain quality of life for the patient, loved ones and other care companions. It is appropriate at any age and at any stage in a serious illness and can be provided along with active treatment. Palliative care facilitates patient autonomy, access to information, and choice. The palliative care team helps patients and families understand the nature of their illness, and make timely, informed decisions about care.

What's the difference between Palliative Care and Hospice and Primary Care?

Many people confuse palliative care and hospice. Hospice care is one kind of palliative care focused on serving patients and families at the end of their lives and usually considered in the last six months of a serious illness. Palliative care can be used at any stage of serious illness and, unlike hospice, can be offered at the same time as curative treatments. Both palliative care and hospice use a team approach to focus on quality of life including the active management of pain and other symptoms, as well as the psychological, social and spiritual issues often experienced with serious illness. While excellent primary care may have some overlaps with palliative care, primary care is more comprehensive and also includes preventive care. Palliative care can be offered within primary care or as a specialty consultative service that supports overall care.

Washington State Department of Health

Northwest TeleHealth

StratisHealth

A public-private partnership of over 24 different orrganizations

To better understand how these programs differ, take a look at this table.

	PALLIATIVE CARE	HOSPICE	PRIMARY CARE
ELIGIBILITY	Palliative care is for people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening. If you or a loved one are suffering from symptoms of a disease or disorder, be sure to ask your current healthcare provider if a palliative care consult would be helpful. Some palliative care programs may have certain eligibility criteria.	Specific to the Medicare Hospice Benefit, a patient is eligible for hospice care if two physicians certify that the patient has six months or less to live if the illness runs its normal course. Patients must be re-assessed for eligibility at regular intervals in order to meet ongoing coverage criteria, but there is no limit on the amount of time a patient can be on the hospice benefit.	Everyone is eligible for primary care, throughout the lifespan. Primary care focuses on preventative care, care for acute illnesses, and management of chronic conditions.
TIMING	There are no time restrictions. Palliative care can be received by patients at any time, at any stage of illness whether it be terminal or not. Should the patient's serious illness become terminal with a prognosis of six months or less, it may be appropriate to consider a referral to hospice care.	Although end-of-life care may be difficult to discuss, it is best for family members to share their wishes long before it becomes a concern.	Most people seek out primary care for preventative visits (e.g. vaccines, well child checks, well woman exams, Medicare wellness exams). They also use primary care when they are not feeling well with an acute illness or are managing a chronic illness such as diabetes.
PAYMENT	Some commercial insurance companies cover palliative care for their beneficiaries. However, Medicare coverage for palliative home care may be challenging due to eligibility requirements. These requirements may include but are not limited to being homebound. If you are unsure of coverage, contact your insurance company.	For those on Medicare, there is a Medicare Hospice Benefit available for patients whose life expectancy is six months or less, as determined by their healthcare provider. Medicaid hospice coverage is the same as the Medicare benefit. Also, most commercial insurance companies also offer hospice coverage. If you are unsure of coverage, contact your insurance company.	Most insurance covers primary care. If you are unsure of coverage, contact your insurance company.
LOCATION	It is most common to receive palliative care through your healthcare provider's office, home care services, hospitals, nursing homes or the patient home.	In most cases, hospice is provided in the patient's home—wherever they may call home which may include their own home/residence, an assisted living facility, a group home or a nursing home. Hospice care is also provided in freestanding hospice facilities, hospitals, or nursing homes.	Primary care is delivered most commonly in clinics. Primary care providers also travel to nursing homes and sometimes make home visits.
TREATMENT	Palliative care focuses on symptom management rather than treatment of disease. It also includes discussions of goals of care at all stages of a disease, and, when appropriate, discussion of choices towards the end of life. Curative treatment can occur concurrent with palliative care.	Hospice programs concentrate on comfort rather than cure. By electing not to receive extensive life-prolonging treatment, hospice patients and their families can concentrate on getting the most out of the time they have left, without some of the negative side-effects that life prolonging treatments may have. Hospice patients may achieve a level of comfort that allows them and their families to concentrate on the emotional and practical issues of dying. The focus of hospice care is more on the quality not the quantity of the life remaining.	Primary care is the day-to-day healthcare given by a clinician; this person may be a physician, a nurse practitioner or a physician assistant. Typically, this provider acts as the first contact and principal point of continuing care for patients within a healthcare system and coordinates other specialist care that the patient may need. A primary care provider is likely to be the person who helps coordinate or refers a patient to palliative care or hospice services. A patient can continue receiving care from their primary care provider while obtaining palliative care or hospice services.

Appendix C. Wisconsin Provider Palliative Care One-Pager

Retrieved from:
http://worh.org/sites/default/files/Lafayette_Provider%20Palliative%20Care%20One%20Pager.pdf

Palliative Care
What Does a Provider Need to Know

What is Palliative Care?	Palliative care, also known as palliative medicine, is specialized medical care for people living with serious illnesses. It is focused on providing patients with relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is appropriate at any age and at any stage in a serious illness. It can be provided together with curative treatment.

Who provides Palliative Care?	Specialist palliative care teams (e.g., physicians, nurses, social worrkers, and chaplains) that provide expert consultation and/or co-management. While palliative care is a medical subspecialty, the principles and many of the practices of palliative care can - and should - be employed by all clinicians that work with seriously ill patients.
	
	Providers in your county include:
	• Hospitals in Lafayette County that Provide Palliative Care
	   o Memorial Hospital of Lafayette County
	• Agencies that Provide In-Home Palliative Care
	   o Agrace PalliaHealth
	   o Hospice of Dubuque

What are the goals of Palliative Care?	The goals is to control symptoms and side effects so patient specific goals of care while also addressing: • Caregiver support • Social support (e.g., transportation, housing, food) • Spiritual support
Who is appropriate for Palliative Care?	• Palliative care is appropriate at any age and at any stage in serious illness, unlike Hospice (i.e., certified prognosis of six or less months) • Based on patient and family need, not prognosis • Can be provided concurrent with disease treatment, unlike Hospice (i.e., forego "curative"care) • If you would not be surprised if the patient expired within the year, they are appropriate for palliative care
Who would benefit the most from Palliative Care?	• One or more serious medical illnesses or multimorbidity • Functional and/or cognitive impairment • Frailty • Frequent hospitalizations or Emergency Service visits • Family caregiver exhaustion
Who pays for Palliative Care?	Fee-for-service provider billing under Medicare Part B, and/or contracts with payers using a range of payment models.

Appendix D. North Dakota Palliative Care Resource

Retrieved from: https://ruralhealth.und.edu/assets/746-17373/palliative-hospice-care-flyer.pdf

Who Is
North Dakota Palliative Care Task Force?

The North Dakota Palliative Care Task Force is committed to improving the quality of life of those facing serious health conditions by promoting patient-centered palliative care and improving access to services. Although it is one of the fastest growing trends in healthcare, palliative care is often misunderstood. The Task Force is set up to develop educational opportunities for providers, patients, and community members to help them clearly understand palliative care and the benefits it offers. The Task Force aims to increase awareness and utilization throughout the state of North Dakota to improve the quality of life of its citizens.

What Is Palliative Care?

Palliative care is specialized medical care for people with serious illnesses. It is appropriate at any age at any stage in a serious illness and can be provided together with curative treatment. Palliative care promotes quality of life by addressing the physical, psychological, emotional, cultural, social, and spiritual needs of patients and families. It offers treatment of pain and other symptoms; relief from worry and distress of illnesses; close communication about goals of care; and well-coordinated care during illness transition. It also provides care across treatment settings and support for family/caregivers and offers a sense of safety in the healthcare system. Palliative care is delivered by a team of physicians, nurses and other specialists who work with the patient's other doctors to provide an extra layer of support.

What Is Hospice Care?

Hospice care is a team approach to expert medical care for individuals who face a life-limiting illness. With a focus on comfort, the team develops a plan of care tailored to each individual's needs and goals. It includes pain and symptoms management, personal care, emotional and spiritual support, and grief support for the each individual's loved ones. All of hospice is palliative care, but not all of palliative care is hospice.

Palliative Care Continuum Timeline

Curative Focus: *Life Prolonging Care*

Prevention/Screening

Palliative Focus: *Comfort/Supportive Treatments*

Care Near the End-of-Life

Bereavement Support

% Focus

Curative — Hospice

Diagnosis — Death

Health — Illness — Death
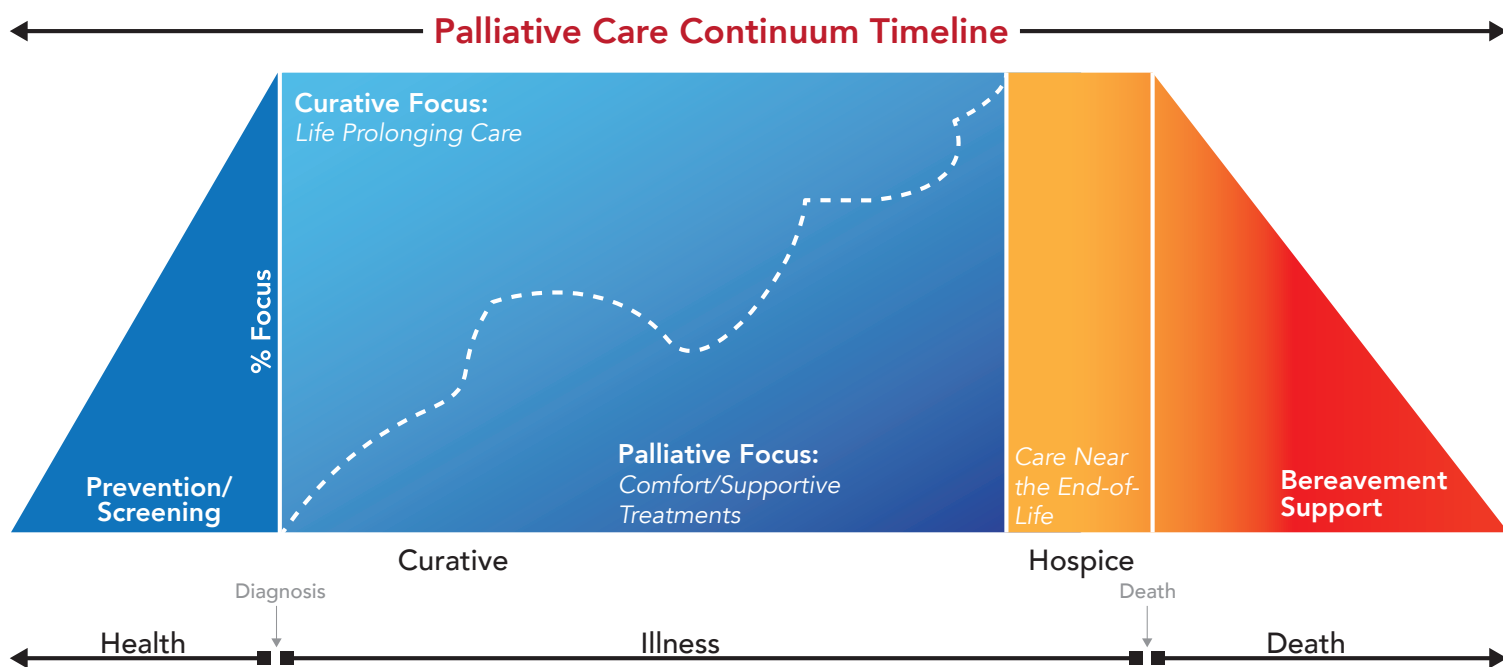
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University of North Dakota
School of Medicine & Health Sciences

ruralhealth.und.edu • 701.777.3848

Palliative Care Continuum Diagram modified from:
• Lynn, J. 2005. Living Long in Fragile Health: The New Demographics Shape End of Life Care. Hastings Report. November-December 2005, S14-18.
• American Cancer Society/Cancer Action Network. 2016 North Dakota Palliative Care Presentation. Bismarck, ND.
• Center to Advance Palliative Care. 2018. Diane E. Meier, Director

	Palliative Care	Hospice
What is the focus of this type of care?	To maximize the patient's quality of life	Comfort care, rather than cure, assist with goals of care, plan for end of life cares
What services are provided?	Manage symptoms, discuss goals of care, pros and cons of treatment options, provide extra support and care coordination	Intensive comfort care that relieves pain and symptoms while attending to an individual's physical, personal, emotional, and spiritual needs
Who qualifies?	Anyone living with a chronic illness or disease; available for anyone at any stage of a serious illness	Patients with a serious life-limiting or terminal illness; supports those with a life expectancy of months, not years
When should we start services?	From the time of diagnosis through treatment and living with the illness	When the patient chooses to stop or go without curative treatments, the focus changes from treating the disease to providing comfort and relieving pain, symptoms, anxiety, and stress
Is a referral required?	No. You can contact us at any time; tell your healthcare provider you'd like to add palliative care to your treatment plan	Yes. A referral is required, and hospice staff can assist with securing a referral from your physician
What are the treatment goals?	Medication education and symptom management, navigating through progression of the illness, support and education for patient and family, advance care planning, and transitioning to hospice, if and when appropriate	Pain and symptom management is key. The patient is always at the center of care, with the goals of helping him/her live comfortably and with a sense of normalcy, respect, and dignity
Does starting this care mean I'm giving up hope?	No. You can continue to pursue the things for which you hope.This includes pursuing curative treatments for your illness alongside palliative care	No. What you hope for may change to focus on comfort, emotional and spiritual peace, and living well at the end of life's journey
Where is care provided?	Home, inpatient facilities, clinic, community, where available	Wherever the patient resides: home, assisted living facility, long-term care facility, hospital, or hospice house, where available
Will this type of care hasten death?	No	No
Does this care mean the doctor has given up?	No. The medical team will continue trying to treat and cure the illness, and palliative care will keep you comfortable	No. The medical team will work together and focus on the reversible causes of pain and symptoms. They are not giving up on you or your comfort
Who pays for services?	Inpatient services are covered as part of the hospitalization, just as other specialists are covered by insurance. Outpatient services are typically billed and covered in a similar way to other outpatient visits	Medicare covers all or most of the services related to the hospice diagnosis. Medicaid and most major insurance companies also offer hospice coverage. No one will be turned down over for inability to pay
Who is involved?	The palliative care team may include a physician, advanced practice providers, social worker, nurses, and chaplain. The team may coordinate care with your primary care provider or specialists	The patient and his/her family work with a multidisciplinary team of experts that may include the hospice medical director, patient's primary physician, hospice nurse, hospice CNA, hospice social worker, hospice chaplain, hospice volunteers, and hospice bereavement specialist
Who provides the care?	Members of the palliative care team, as noted previously, provide both direct and indirect care.	The entire care team: doctors, nurses, CNAs, social workers, chaplains, volunteers, bereavement specialists, and others as needed
Will this service help my family?	Yes. They are part of the support system. Family members are encouraged to participate in palliative care visits as appropriate	Yes. They are an integral part of the support team

Appendix E: Washington Site Visit Report

This site visit report is part of an evaluation of the Rural Community-Based Palliative Care Project funded by Stratis Health. The NORC Walsh Center for Rural Health Analysis is conducting the evaluation, which will highlight efforts to develop and implement community-based palliative care in rural areas across three states: Washington, North Dakota, and Wisconsin. This report highlights key findings from NORC site visits to two Washington communities in late 2019 and a phone interview with Pat Justis, executive director of the Washington State Office of Rural Health and leader of the Washington Rural Palliative Care Initiative.

RURAL COMMUNITY-BASED PALLIATIVE CARE INITIATIVE

In 2017, Stratis Health, a nonprofit organization focused on health care quality and innovation, embarked on an effort to increase access to and quality of community-based palliative care (CBPC) services in rural communities in three states: Washington, North Dakota, and Wisconsin. Led by State Offices of Rural Health, each state identified a cohort of communities to participate in the initiative. Seven communities were selected in Washington and are currently in various stages of development and implementation. NORC visited two communities that have established their palliative care program and are now seeing patients. These two communities are described below.

Community A	Community B

▪ *Located in southeastern Washington, population 2,535; CBPC is part of a county health system*
 ▪ *Located in a designated Health Professional Shortage Area and a Medically Underserved Area*
 ▪ *CBPC services and processes comprise:*
    ▪ *Adult/geriatric nurse practitioner*
    ▪ *Case management for chronic disease*
    ▪ *Bereavement care (apart from hospice)*
    ▪ *Community health workers*
    ▪ *Hospice care*
    ▪ *Medical social worker*
    ▪ *Pain management consultation*
    ▪ *Pastoral care/chaplaincy*
    ▪ *Support groups, such as caregiver support groups or grief support groups*
    ▪ *Transportation*
	▪ *Located in southeastern Washington, population 34,019; CBPC program is part of a regional hospital*
	 ▪ *Located in a designated Health Professional Shortage Area*
	 ▪ *CBPC services and processes comprise:*
	    ▪ *Physician assistant*
	    ▪ *Case management for chronic disease*
	    ▪ *Bereavement care (apart from hospice)*
	    ▪ *Home health services (medical care)*
	    ▪ *Hospice care*
	    ▪ *Medical social worker*
	    ▪ *Pastoral care/chaplaincy*
	    ▪ *Respite care for family caregivers apart from hospice*
	    ▪ *Support groups, such as caregiver support groups or grief support groups*

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WASHINGTON STATE MODEL

Rural leaders in Washington recognized an unmet need for rural palliative care services in the state. Over the course of several meetings, these leaders outlined a model for implementing CBPC that encompassed community engagement; culture change (i.e., shifting which/how clinical skills are used); clinician education; and telehealth. Steered by the Washington State Office of Rural Health (WSORH), the Washington Rural Palliative Care Initiative (WRPCI)[1] emerged as a valuable resource comprising public and private organizations that support rural communities with the capacity and interest to engage in CBPC. Stratis Health provides financial support and technical assistance to WSORH.

COMMUNITY IMPETUS

Interest in palliative care in both communities grew out of recognition of its value in meeting the needs of residents with serious illnesses. Champions of palliative care were also key to its integration into the communities' health care delivery systems. These individuals shared their passion and enthusiasm for this approach to care and found others who were willing to listen with an open mind about how they could adapt it in their community. Community A explained how a hospital board member was inspired by Atul Gawande's *Being Mortal*, a book that focuses on end-of-life care, and encouraged all board members to read it. The community then hosted a public viewing of a PBS documentary about the author, demonstrating efforts to engage the community at large from the start.

LEADERSHIP

Critical to the success of the palliative care programs are strong leadership and program champions—team members who support and advocate for palliative care. This is a premise that Pat Justis emphasized during our conversation and the communities demonstrated during our visits. Both communities have strong leaders, though different leadership structures and styles. The hospital CEO of Community A comes from a health IT background and brings a unique outsider

perspective to challenges and opportunities. The CEO is open to new ideas, such as end-of-life care, to meet the aging-in-place emphasis that is a marker of the hospital and the broader health system the hospital anchors. The CEO supports solutions offered by his staff and encourages their ideas. Community A's chief nursing officer works closely with the CEO to implement and coordinate the program.

Community B also has a strong leader with a disciplined health care background in nursing (RN, BSN), who was engaged as the clinical project manager to give structure to the emerging palliative care program at the hospital. The program coordinator strives to make sure ideas are carefully considered before implemented, and appreciates small steps toward achieving a larger goal. Community B is supported by an advisory team comprising the hospital's chief clinical officer, social services director, hospitalist medical director, MedSurg/ICU director, and the clinical project manager. The advisory team helps to balance the palliative care team's routine workload with palliative care responsibilities. Both leaders are surrounded by passionate and adept team members who share their leaders' enthusiasm, commitment, and willingness to think outside the box.

> *Community B on Leadership: "You've got to have a personality that can be flexible... If you're rigid and you need to do it certain ways… you're going to struggle. But I don't think most rural communities have those types of personalities. They have independent people, but they have had to do things differently to make it work and it usually involves a team of people; they don't usually do it alone."*

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[1] Washington Rural Palliative Care Initiative, https://waportal.org/partners/home/washington-rural-palliative-care-initiative.

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HOW PROGRAMS ARE STRUCTURED

The Washington community programs we visited are structured similarly, where a critical access hospital serves as the basis for the program and both in-patient and out-patient services are offered. Referrals for patients are common following an in-patient stay or same-day service (Community B). Key team members include a physician assistant, registered nurses, social workers, and a pharmacist. Community A also includes a physician's assistant, community health workers, acupuncture, and massage therapy. Nurses use telehealth by bringing an IPad into the patient's home and using Zoom webinar technology to consult with palliative care providers at the hospital or clinic. Community B has an advisory board of hospital department heads that meets monthly to discuss updates and help manage the workloads of staff providing palliative care. The communities also work with other local health and social service providers, such as aging services or housing. Both communities serve only adult patients, and of those, most are older adults.

TRAINING

Various members of the palliative care teams have had formal training in palliative care, but not all. In Community A, certified nursing assistants, social workers, and nurses completed training in end-of-life care. Training opportunities exist through the Center to Advance Palliative Care,[2] the Washington Rural Palliative Care Initiative, and monthly consortia meetings with other Washington communities. Both communities have used VitalTalk[3] as a training resource on having difficult conversations. Two members of Community B have been trained in the End-of-Life Nursing Education Consortium (ELNAC)[4] and teach others about palliative care at the hospital. Community A also offers caregivers the opportunity to participate in the STAR-C[5] training program, which educates and arms caregivers with skills to help them manage their care recipient's challenging behaviors related to Alzheimer's disease.

WRPCI SUPPORT

In addition to offering training to communities, WRPCI convenes a monthly advisory team meeting with community leads and other invitees, facilitates operational round tables, hosts mentoring calls, and provides telehealth case consultation. WRPCI also supports a web-based portal that hosts palliative care resources and offers space for communities to discuss panel cases. Specific community needs that WSORH supports include the establishment of operational processes (e.g., patient discharge criteria) and guidance on convening an interdisciplinary group of rural providers. To improve understanding of insurer billing codes relevant to palliative care, WRPCI hosted a billing workshop that addressed coding and required documentation.

IMPACT

Clinical impact. Both communities reported that they have observed reductions in emergency department (ED) visits for patients in their palliative care programs. It is difficult, however, to align the utilization shifts directly to cost savings. As Community A pointed out, cost-savings from fewer ED visits are sometimes hidden among the various wraparound services engaged in palliative care; the true health care costs are underestimated because these wraparound services may not be included in the total cost of palliative care. Often, costs per beneficiary increase upon initiation of palliative care services, then decrease. The flow of services and lag in data can also affect the estimate of cost benefits. For example, Community A admitted a number of patients with different levels of acuity and complications, but all of them ultimately became learning opportunities. Community B highlighted the team's follow-up phone calls with patients as an important strategy in reducing ED visits.

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[2] https://www.capc.org/training/.
[3] https://www.vitaltalk.org/.
[4] https://www.aacnnursing.org/ELNEC/About.

[5] https://livingwell.doh.wa.gov/Portals/10/Doc/One%20Pagers/STAR-C.pdf.

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Take the Quiz:
Is Palliative Care Right for You?
Answer the following questions to determine wheth-
er palliative care might be right for you or someone
close to you. Remember, you can receive palliative
care at any point in your illness.

1. Do you have one or more serious illnesses
such as:

- Cancer
- Congestive heart failure (CHF)
- Chronic obstructive pulmonary disease
  (COPD), emphysema, lung disease
- Kidney failure
- Liver failure
- Neurological diseases (e.g., ALS, Parkinson's)
- Dementia

Figure 1: Community A Program Brochure

Caregiver impact. Our team talked with two palliative caregivers in Community B, one in person and the other by telephone. Both caregivers praised the palliative care program. The first caregiver was grateful for the social worker's help with coordinating her partner's care, their finances, and facilitating respite for one month. The second caregiver described how the team provided information about the program and explained the difference between hospice and palliative care, and also helped her to understand what was happening with her husband. The care team checked in with the caregiver during an ED visit, and the "friendly face" helped with the caregiver's stress during that time. In addition, the caregiver noted how easy it was to reach the team on the phone, and found the resources they provided, such as one on communicating with dementia, especially helpful. She also mentioned that she is unsure how to use some resources, such as respite. All in all, however, the caregiver was "relieved to have someone else involved."

CHALLENGES AND LESSONS LEARNED

Reimbursement. The primary challenge identified by the Washington communities was inadequate reimbursement. As Community A described, there are lots of costs associated with providing the wraparound care that they offer. Some care can be billed (e.g., providers, advanced care planning, behavioral health, telehealth). Yet for other services, reimbursement avenues are available through the Chronic Care Management program, which both communities have implemented as part of their ACOs, in addition to Accountable Communities of Health funding. However, these reimbursements are insufficient to cover all of the costs of care and resources provided to patients and their families. Both teams find themselves "squeezing" in some of the palliative care they provide between their regular workload, creating stress on the teams. The request for more time was a frequent comment made by staff. Despite the challenges associated with lack of reimbursement and overflowing workloads, all staff we spoke with revealed an incredible dedication not just to the palliative care patients and their teams, but to the idea of palliative care and its advancement in their communities.

Education. Another challenge encountered by both communities is education on palliative care for providers, patients, families, and the community at large. Provider buy-in is critical to ensuring the success of a palliative care program. Without education, providers may not understand the role that palliative care can play in a patient's overall health and well-being. They may not see its value, or believe that palliative care will replace the primary care provider's role in the patient's care. Community A cited the importance of educating providers early, so that their collaboration with the palliative care team can be productive from the beginning. Patients and family members also need education about palliative care, especially the difference between palliative care and hospice. Both communities indicated their desire to conduct more community education, but cited a lack of resources or lack of program stability to feel confident in widening their reach at this time.

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CONCLUSION

The rural Washington CBPC programs that we visited have developed a sound foundation on which to build and expand. As we observed, leadership and a dedicated team of professionals are instrumental to the program's success. Despite the challenges associated with reimbursement and lack of stakeholder education, the programs have persevered and found creative ways to mitigate these challenges. The sustainability of such creative workarounds is uncertain.

The WRPCI will continue its support of current consortia members and is planning to invite a second cohort of communities to join the initiative. The second cohort will be funded in part by a grant from Cambia Health Foundation, which is focused on building community capacity. Future opportunities and priorities for the group include additional testing of telemedicine with patients and families who generally prefer in-person care; expanding the use of telemedicine with patients at clinical sites; process measurement within communities; and onsite training for clinical palliative care skills development (i.e., advancing culture change). The WRPCI recognizes, however, the need to balance its work on strategic development and innovation with the technical support it provides to member communities.

We would like to acknowledge the communities in rural Washington for opening their palliative care programs to us, and to Pat Justis, for sharing her time and reflections on the state of Washington's efforts in supporting rural CBPC.

The information, conclusions, and opinions expressed in this report are those of the authors. No endorsement by Stratis Health or NORC at the University of Chicago is intended or should be inferred.

For More Information:

Stratis Health Rural Palliative Care: http://www.stratishealth.org/expertise/longterm/palliative.html

Appendix F: North Dakota Site Visit Report

This site visit report is part of an evaluation of the Rural Community-Based Palliative Care Project funded by Stratis Health. The NORC Walsh Center for Rural Health Analysis is conducting the evaluation, which will highlight efforts to develop and implement community-based palliative care in rural areas across three states: Washington, North Dakota, and Wisconsin. This report highlights key findings from NORC virtual site visits to two North Dakota communities in late 2020 and an early 2021 phone interview with Nancy Joyner, subject matter expert at the Center for Rural Health, University of North Dakota, and Jody Ward, principal investigator of the North Dakota Rural Community-Based Palliative Care Project at the Center for Rural Health, University of North Dakota.

RURAL COMMUNITY-BASED PALLIATIVE CARE INITIATIVE

In 2017, Stratis Health, a nonprofit organization focused on health care quality and innovation, embarked on an initiative to increase access to and quality of community-based palliative care (CBPC) services in rural communities in three states: Washington, North Dakota, and Wisconsin. Led by State Offices of Rural Health, each state identified a cohort of communities to participate in the initiative. Nine communities were selected in North Dakota and are currently in various stages of development and implementation. NORC conducted virtual site visits to two communities that established palliative care programs and are seeing patients. These two communities are described below.

Community A	Community B
• Located in central North Dakota, county population 13,800[1]; CBPC is part of a critical access hospital	• Located in western North Dakota, estimated population 15,024[3]; CBPC program is part of a critical access hospital
• Located in a designated Health Professional Shortage Area (Geographic – Primary Care; High Needs Geographic – Mental Health)[2]	• Located in a designated Health Professional Shortage Area (Geographic – Dental, Primary Care; High Needs Geographic – Mental Health) and Medically Underserved Population [Ibid].
• CBPC services and processes comprise:	• CBPC services and processes comprise:
○ Case management for chronic disease	○ Adult/geriatric nurse practitioner
○ Community health workers	○ Case management for chronic disease
○ Home care (supportive care)	○ Pastoral care/chaplaincy
○ Home health services	○ Support groups, such as caregiver support or grief support groups
○ Hospice care	○ Visiting nurse
○ Medical social worker	
○ Pastoral care/chaplaincy	
○ Support groups, such as caregiver support groups or grief support groups	
○ Transportation	

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[1] https://www.hrsa.gov/sites/default/files/hrsa/ruralhealth/resources/hrsa-rural-collaboration-guide.pdf
[2] https://data.hrsa.gov/tools/shortage-area
[3] https://www.census.gov/quickfacts/mckenziecountynorthdakota

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NORTH DAKOTA STATE MODEL

Of the very few palliative care programs that existed in rural North Dakota prior to the initiation of the Stratis Health project, most worked in silos. Interest in palliative care at the state level was a catalyst for the formation of the North Dakota Palliative Care Task Force in 2017, which aimed to explore the importance of palliative care and the need for resources and best practices to provide better care to North Dakotans with chronic illnesses. Efforts to enhance palliative care education and access were thus underway when Stratis Health engaged North Dakota in the Rural Community-Based Palliative Care Project. Through the project, the North Dakota State Office of Rural Health initially identified eight critical access hospitals (CAH) in the most sparsely populated rural communities to participate in the project. These communities were chosen because of their rurality and the lack of a large health system in close proximity to them. As one state lead described, "if a palliative care program can work in these rural places, they can work anywhere." Throughout the project, the North Dakota State Office of Rural Health and Stratis Health provided technical assistance to participating communities.[4]

COMMUNITY IMPETUS

The North Dakota palliative care programs we visited virtually grew organically out of a shared recognition of the need for palliative care in their areas. In Community A, an established hospice program laid the foundation for palliative care. Hospice staff recognized the need for wrap-around services to support local residents with terminal illness. Some of these staff members were already participating in monthly accountable care organization (ACO) meetings where interdisciplinary work was inherent, paving the way for an extension of that interdisciplinary work under the umbrella of palliative care. Likewise in Community B, hospice care existed, albeit limited, and staff had also identified gaps in services (e.g., lack of home health care). Using palliative care resources (e.g., needs assessment) made available by Stratis Health and leveraging their own passion, each team member from Community B assumed different roles and responsibilities (e.g., advance care planning, discharge planning) to implement the new program.

LEADERSHIP

A key facilitator to move the programs forward were individuals passionate about palliative care and palliative care access in their communities. Community A also has a transformation-focused CEO, who is well respected and was regarded as a champion for the community and for home and community-based services. Others who would later comprise the palliative care team also recognized the need for palliative care as well, but were unsure where to start and how to make the program work for their rural community. Prior to joining the Rural Community-Based Palliative Care Project, they sought guidance from other communities.

HOW PROGRAMS ARE STRUCTURED

Patients in Community A are referred to the program from a provider, the local Federally Qualified Health Center (FQHC), or the Community Care Program, a partnership between Community A's CAH and the FQHC to provide clinical assessments in the home, offer clinical services (e.g., blood draws, medication set-up), and connect individuals to community services. Most patients in the Community B program are referred as patients from the CAH. Both programs integrate regular in-home visits, though the type of provider who conducts the home visit is different for each program. For Community A, the patient's primary care provider (PCP) conducts monthly visits and/or monthly phone calls, but the PCP is not a member of the palliative care team. The palliative care team works with the Community Care Program, to partner with services in the community. In Community B, the chronic care manager/visiting nurse and the program manager—both from the palliative care team—conduct the in-home visits. Members of the interdisciplinary team, including the medical director, social worker, nurses, and pastor, meet monthly to review changes to patients' care.

Both programs noted that palliative care helps patients stay at home. The home environment was cited as an important component of the programs, allowing patients to receive care where they are comfortable. In particular, Community B described how the home allows for more of a connection with the patient and where they (providers) can elicit more information through observation. For example, staff members are better able to assess mental

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[4] https://ruralhealth.und.edu/projects/community-palliative-care

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health status and the home environment (e.g., fall prevention). Visiting patients in the home also allows for needs to be identified sooner, since providers are able to understand additional context from the home environment as well as from household and family member dynamics. As Community A described, palliative care allows time for listening, which "does more than medicine."

> **Chaplain's Role**
>
> In Community A, the chaplain is a valued part of the team, and the team recognizes that spiritual care is important and would like to utilize it more. The chaplain conducts an initial visit with the patient once they are admitted to palliative care, then continues as the patient's pastor or facilitates a connection to the patient's regular pastor. The chaplain we spoke with reflected on how he understands that palliative care patients are experiencing multiple stages of grief, and how patients feel challenged to reach their goals. This conversation highlighted the insightful nature of the pastor, a characteristic valued by his team members. As one provider quipped when asked for advice on implementing palliative care programs, spiritual and emotional needs are not "fixed with a pill."

TRAINING

Staff members in both programs have taken advantage of various palliative care training opportunities, including those offered by Stratis Health and other organizations such as CAPC, the Center to Advance Palliative Care.[5] Topics have included the Edmonton Symptom Assessment Scale[6], POLST[7], and advanced directives[8]. Both programs have joined CAPC, which provides a wealth of resources and training opportunities for providers, programs, and health systems aiming to improve access to palliative care. Additional staff training was cited as an ongoing need.

IMPACT

Patient Satisfaction. Both programs reported high levels of patient satisfaction. Community A described how patients feel comfortable with the palliative care team in their home, and at times, the palliative care team is their only contact with someone outside their home. One provider from Community B reported that a family liked the support the palliative care team provided and how they were able to maximize the time the patient remained in their home. This kind of positive feedback can have significant impact on a team's motivation, and Community A providers specifically expressed that they feel they are making a difference.

Soft Transition to Hospice. This emerged as an important theme during both virtual site visits. A soft transition from palliative care to hospice was perceived by staff to support patients' timely decision to begin hospice care and was attributed to the success of the programs. Staff described how the transition to hospice care, when appropriate, was much smoother if the patient had already been in palliative care. A common barrier to this transition is a resistance to hospice care, as hospice care is often equated with end-of-life. Consequently, patients may postpone hospice care, missing out on benefits that may enhance their quality of life. According to a Community B provider, a caregiver shared that palliative care was a "bridge" that helped her on her family member's journey. It allowed the patient to die with peace and joy. A Community A provider explained that entering into palliative care first, and especially in a program where the palliative care staff members are part of the hospice program, ensures they will encounter familiar faces and providers in whom they have already developed trust when they need hospice care. In small rural programs where palliative care and hospice staff overlap, this opportunity for continuity of care may be inherent.

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[5] https://www.capc.org/
[6] http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf
[7] https://polst.org/form-patients/
[8] https://www.nia.nih.gov/health/advance-care-planning-health-care-directives

CHALLENGES AND LESSONS LEARNED

Reimbursement. Financial support for palliative care services is one of the biggest challenges sited by North Dakota programs. Limited reimbursement mechanisms mean that teams must creatively structure their workflow to ensure a sufficient amount of their work is billable and spend time and energy on novel ways to financially sustain their work. For example, maximizing reimbursement opportunities for certain providers (e.g., nurse practitioners) helps to support the work of other staff (e.g., nurses or social workers). Community B described how some care provided by their palliative care teams may be reimbursable under chronic care management, advance care planning, or hospice respite. Both programs are part of ACOs, which provide shared savings opportunities for health care entities that aim to provide high-quality coordinated care for Medicare beneficiaries that results in lower health care costs.[9] Community A relies on the Community Care Program, described above, to address some of the unmet needs of palliative care patients (e.g., home monitoring devices such as Lifeline) such as helping patients enroll in Medicaid. Community A considered increasing awareness of their services in larger markets where some of their patients currently seek treatment, hoping to partner with a larger health system to educate patients about the resources available to them locally (and eliminating long travel times). Keeping patients local and garnering community buy-in would help ensure demand for palliative care services. One feature both programs agreed on was the benefit of a dedicated provider who oversees palliative care treatment for all patients. The provider would be separate from the patient's PCP and would coordinate care plans with the PCP. As one program reflected, not all PCPs recognize the need for a designated palliative care provider. Without adequate funding, programs may not be able to offer things like equipment to support safely remaining in the home, such as shower chairs and a grab bar.

Education. Another important challenge and opportunity for growth is education about palliative care, which applies across the range of stakeholders, from patients and caregivers to providers and the community at large. One of the most common misunderstandings about palliative care for patients, caregivers, and the public is that this type of treatment signals the end of life, and as

Community B pointed out, this can be a barrier to using palliative care. Buy-in among the public is also influenced by community characteristics, including the desire for independence or a transient population (e.g., seasonal workers) to whom services may not be sought. For providers in particular, there can be a reluctance to recognize the need or value of palliative care. Likewise, providers may not welcome a dedicated palliative care provider to the patient's health care team, or be aware of the array of services available to palliative care patients.

> **Rural Community Engagement Strategies**
>
> To counter misunderstanding about palliative care, Community B tried to engage the community at various public awareness events including public meetings and stakeholder groups, developed a brochure about palliative care, and is currently working with the chamber of commerce to increase awareness.

When reflecting on the value of learning opportunities, such as webinars focused on palliative care, Community A providers agreed that information needs to be tailored to rural settings given that the depth and breadth of rural resources may be more limited than in urban settings. For example, pharmacy services are not available 24 hours a day/7 days per week in Community A. In the middle of the night if a patient needs a prescription filled, providers call the pharmacist at two or three in the morning.

COVID-19. A singular challenge to the implementation of North Dakota palliative care programs in 2020 was the impact of the coronavirus pandemic. When we spoke with communities in the fall of 2020, North Dakota had the highest rate of COVID-19 infections in the country, though the pandemic had begun to take its toll on their work in the spring. In-home visits were scaled back and any public awareness events were canceled. Yet, the COVID-19 public health emergency affected the two communities' palliative care programs differently.

Community A described how it was feasible to continue to provide care with smaller numbers of patients, transitioning to remote care via telephone

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[9] https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO

and making in-home visits when possible. They began using telehealth, via iPads and Zoom, to have visits with patients. While they worried about staffing and the inability to treat nursing home residents, a positive outcome that emerged for their program was the use of a dedicated provider (i.e., PCP) to oversee patient care given pandemic restrictions. It should be noted that this program had been established well before the second community, which likely contributed to their ability to adapt to changes in response to the pandemic.

Community B continued work on policies and procedures and conducted more advance care planning, as well as some virtual office visits. However, they noted that palliative care was pushed to the backburner as priorities shifted in patient care.

CONCLUSION

The two North Dakota palliative care programs are structured similarly, based in a CAH, and comprised of similar types of staff. The program staff members also share the same passion and dedication to bring palliative care to their communities. In addition, they share similar challenges, primarily lack of reimbursement options and limited awareness about palliative care. Both program teams streamlined workflows and increased efforts to educate key stakeholders.

The North Dakota State Office of Rural Health is committed to continuing their role in increasing access to palliative care, while program staff members at participating North Dakota Rural Community-Based Palliative Care Project communities plan to maintain the relationships and support systems they have built with one another. Although the pandemic may have slowed down the progress of rural North Dakota palliative care programs, dedicated stakeholders are committed to staying the course.

When program staff and state leads were asked what advice they have for other rural communities interested in implementing a palliative care program, they offered the following suggestions and guidance:

- Appreciate that palliative care "doesn't have all the rules" such as Medicare rules pertaining to home health services.

- Identify a dedicated provider (e.g., advance practice provider) for home visits.

- If feasible, consider establishing the palliative care program within the hospice team when there is not enough demand for full-time palliative care staff.

- Start small with targeted populations to establish an initial workflow.

- Problem solve together. Be inclusive. "One person can't move a mountain, but 10 people can." Identify your strengths and limitations.

- Consider state resources and grant funding to finance palliative care.

- **Keep going, keep learning!**

For More Information:

Stratis Health Rural Palliative Care: http://www.stratishealth.org/expertise/longterm/palliative.html

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Appendix G: Wisconsin Summary Report

This summary report is part of an evaluation of the Rural Community-Based Palliative Care Project funded by Stratis Health. The NORC Walsh Center for Rural Health Analysis is conducting the evaluation, which will highlight efforts to develop and implement community-based palliative care in rural areas across three states: Washington, North Dakota, and Wisconsin. This report summarizes phone interviews in late 2020 and early 2021 with three Wisconsin project stakeholders: Ann Patek, Director of Palliative Care at Ascension Wisconsin; Julie Schmelzer, Project Specialist at MetaStar; and Kathryn Miller, Rural Hospitals & Clinics Program Manager at the Wisconsin Office of Rural Health.

RURAL COMMUNITY-BASED PALLIATIVE CARE PROJECT

In 2017, Stratis Health, a nonprofit organization focused on health care quality and innovation, embarked on an initiative to increase access to and quality of community-based palliative care services in rural communities in three states: Washington, North Dakota, and Wisconsin. Led by State Offices of Rural Health, each state identified a cohort of communities to participate in the project. Four health care organizations in Wisconsin were selected to lead work within counties they serve to help existing palliative care providers (e.g., hospitals, palliative care agencies) implement the Rural Community-Based Palliative Care Project. The health care organizations and palliative care providers were referred to as "coalitions."

Coalition A
• Located in northern Wisconsin, county population 35,381[1]; CBPC is offered at two local hospitals
• Located in a designated Health Professional Shortage Area (Population – Primary Care, Dental Health)[2]
• CBPC services and processes comprise:

o   Adult/geriatric nurse practitioner
    o   Home health services (medical care)
    o   Hospice care
    o   Medical social worker
    o   Pain management consultation
    o   Pastoral care/chaplaincy
    o   Support groups, such as caregiver support groups or grief support groups

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[1] https://data.census.gov/cedsci/table?q=Oneida%20County,%20Wisconsin%20Populations%20and%20People&tid=ACSST5Y2019.S0101&hidePreview=false
[2] https://data.hrsa.gov/tools/shortage-area

WISCONSIN STATE MODEL

Stratis Health engaged the Wisconsin (State) Office of Rural Health (SORH), who subcontracted with MetaStar, as a participating partner in the Rural Community-Based Palliative Care Project. According to an environmental scan produced in 2018 by MetaStar, Inc. for the project, palliative care is offered by health care systems or palliative care organizations in all but one county in Wisconsin (64 percent of Wisconsin counties are defined as rural).[3] Given the coverage of palliative care in rural Wisconsin, project leadership chose to focus their efforts on education and increasing referrals to existing palliative care programs. Four health care organizations were identified to work closely with communities where they provide services to implement palliative care education initiatives around the state. These local partnerships between lead health care organizations and community palliative care providers were referred to as "coalitions." The SORH offered support to coalitions by providing presentations on palliative care tailored to different audiences (i.e., providers, community-at-large, and assisted living facilities).[4]

IMPLEMENTATION EXPERIENCE

Using tools provided by Stratis Health, one participating coalition identified gaps to increasing access to available palliative care services. The coalition implemented its Rural Community-Based Palliative Care Project initiative in a single county in northern Wisconsin where poverty (8.9%) and uninsured (6.3%) rates[5] were a concern. Two hospitals in the county were part of the coalition and already offered some palliative care services, but wanted to expand those services further into the rural community. Citing misconceptions about palliative care on the part of providers *and* community members, the coalition focused their energy on education and awareness. Many providers and community members referred to palliative care and hospice interchangeably; this misunderstanding may inflate the number of palliative care programs reported to be offered in Wisconsin. The coalition found that community members often resisted palliative care, likely due in part to their misunderstanding of how and when it

may be used, stating they were "not ready for palliative care." For providers, a misunderstanding about palliative care can impede successful transitions of care.

> **Rural Community Engagement Strategies**
>
> The WI rural palliative care coalition described how long-standing relationships between providers and patients in rural areas could facilitate use of palliative care. When new providers, who were unfamiliar with palliative care, assumed the care of palliative care patients in different settings (e.g., transition from in-patient hospital to a skilled nursing facility), the continuity of palliative care may be interrupted. The coalition sought to address these types of challenges related to education with resources and tools tailored to the audience.

CHALLENGES AND LESSONS LEARNED

Sustainability. The COVID-19 pandemic affected the coalition's efforts to improve understanding of palliative care. Staff were re-deployed to other roles in the hospital, and in-person visits were limited at skilled nursing facilities. Public presentations were also canceled. This slowdown in their communication efforts and momentum, coupled with a change in coalition leadership to others in the health system unfamiliar with northern Wisconsin, impeded the coalition's education campaign. A new, third hospital built in the area may further compound the coalition's work, should there be additional competition for palliative care services and a change in patients seeking their services.

When COVID-19 restrictions are lifted, the coalition is well positioned to reengage their communication strategy deploying the materials that have already been created, such as PowerPoint presentations and a one-page resource guide. Interest exists within the coalition to maintain the progress made on palliative care education post grant funding. A dedicated Advance Care Planning initiative within the health system may align with the efforts of the

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[3] http://worh.org/sites/default/files/WI%20Environmental%20Scan.pdf
[4] http://worh.org/rural-community-based-palliative-care
[5] https://www.census.gov/quickfacts/fact/table/oneidacountywisconsin/PST045219

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coalition and integrate palliative care education into their work.

Lessons Learned. The coalition offered suggestions for other rural communities seeking to improve understanding of palliative care.

- Take the time needed to ensure providers and community members understand what palliative care is and how it differs from hospice care.

- Create an opportunity to reach out to new providers to introduce them to the palliative care services offered in the community, which can help ensure continuity of palliative care during care transitions with these providers.

- Integrate palliative care for seriously ill patients across all care settings.

We would like to acknowledge Ann Patek for sharing her experiences with the Rural Community-Based Palliative Care Project, and to Julie Schmelzer and Kathryn Miller for their reflections on the state of Wisconsin's efforts in supporting rural community-based palliative care.

The information, conclusions, and opinions expressed in this report are those of the authors. No endorsement by Stratis Health or NORC at the University of Chicago is intended or should be inferred.

For More Information:

Stratis Health Rural Palliative Care: http://www.stratishealth.org/expertise/longterm/palliative.html

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