The John A. Hartford Foundation
Tipping Point
CHALLENGE

Washington Rural Palliative Care Initiative - A Statewide Learning Community

Submitted by: Washington State Department of Health

Silver Winner

Innovation Challenge

Overview

The Washington State Department of Health made it our mission to address the lack of equitable access to palliative care in Washington State's rural communities. While palliative care expanded in urban areas, particularly in hospitals, the specialty had not been integrated into rural health systems or community settings—only one-third of patients in these communities had access. Even fewer rural settings could work upstream to identify and screen patients for palliative care early in the disease trajectory.

The solution: the Washington Rural Palliative Care Initiative (WRPCI). This initiative uses a combination of community-driven design, a peer-to-peer mentoring network, telehealth case consultation, and more to help rural health systems and communities integrate palliative care across various settings to better serve people living with a serious illness, and their families.

Impact

People living with a serious illness who live in rural communities tend to be older, under-insured, and experience higher mortality rates. Additionally, they have limited access to specialty providers despite being more likely to suffer from chronic conditions or physical disabilities. In general, rural populations are of lower socioeconomic status than those living in urban areas, yet they have less access to palliative care and other support. The WRPCI program aimed to address this by helping rural health systems and communities integrate palliative care across settings.

Prior to participating in the WRPCI program, rural palliative care community teams reported significant deficiencies in experience/expertise in managing serious illness conversations, processes for care transitions, and pain and symptom management. Those wanting to offer palliative care faced barriers associated with a lack of local expertise, clinical training, resources, limited caregiving/home health availability, staff turnover, and administrative resistance to funding for dedicated palliative care staff, given low volume.

Isolated geographically, and increasingly so during the COVID pandemic, communities attempted to address the concerns of patients and families with a jack-of-all-trades approach. One chief administrative officer (CAO) acknowledged, “We don’t know what we need or when we’ll need it until we need it.” WRPCI’s experience has been met with adequate support, enabling local communities to provide palliative care services effectively. The models of delivery have significantly varied from community to community.

As far as impact, the original cohort of seven in (2018) has expanded to three cohorts, spanning 20 communities (as of 2023). Each cohort has been supported in developing community-specific goals and setting a pace that is realistic for them. Any growth is celebrated, as the WRPCI recognizes that each program is the expert in their own community. No matter the community demographic or geographic isolation, they have all acknowledged that WRPCI has served as a lifeline in this overwhelming work.

Changing staff has impacted the participation level of each community, but the anchor and stable presence of the WRPCI has allowed health systems to step back and rejoin the initiative when able. Multiple sites are in the process of expanding services to outpatient settings, rehab facilities, or the emergency department (ED), while others are rejoining post-COVID.

The WRPCI brings together 20 communities for individual mentoring, education opportunities, conference attendance, access to Center to Advance Palliative Care (CAPC) resources, and a monthly team-based interdisciplinary case consultation designed to increase the confidence of local community caregivers.

A series of focus groups (conducted in the fall of 2023) revealed verbalized satisfaction with the initiative from all respondents. They noted a sense of empowerment, decreased isolation, and recognition that there are accessible resources despite the isolation they feel from receiving palliative care in their rural communities. Both qualitative focus group feedback and quantitative survey responses indicated across-the-board support for the WRPCI. One respondent noted that no matter how much she was pulled in other directions during her work week, a monthly telehealth consultation “refreshes my spirit and brings my providers together as a team.”

Outcomes

The WRPCI is a pilot to better serve rural patients, their families, and providers who have been impacted by serious illness. The initiative rests on four basic realms of intervention: community engagement; clinical skill and culture change; a combination of telehealth case consultation and direct clinical telemedicine delivered to patients and families by palliative care experts; and increased sustainable funding.

The initiative has multiple disciplines and a purposeful mix of rural health, specialty palliative care, and telemedicine expertise. The communities follow national palliative care standards that call for an interdisciplinary approach. The team-to-team case consultation we conduct via telehealth uses an interdisciplinary team interaction on both “ends” and accesses disciplines that are unavailable in the local community. Each discipline, perspective, and set of skills add to our synergistic ability to comprehensively respond to the patient and family’s needs, values, and preferences.

In June 2018, a workgroup launched a case consultation pilot learning community that met twice monthly for six months. An RN coordinator assisted sites in the selection and presentation of the cases. A Plan Do Study Act (PDSA) process has created a culture of continuous improvement. The Flex program has supported the program under the guidance of the Washington State of Office of Rural Health, grant funds, and the dedication of interdisciplinary palliative professionals and the cohorts. The most recent accomplishments include the initiation of the third cohort (across eight new sites) and ongoing telehealth consultations that continue to meet monthly during 2022-23. A portal is updated where all members have access to palliative care information, training updates, summaries of case consults, contact information, and data.

In 2022-23, learning opportunities included three-panel discussions; a continuing medical education (CME) series of online communication and symptom-related education opportunities funded by Cambia Foundation; real-time case consults with a palliative care doctor (MD) and licensed independent clinical social worker (LICSW); cohort mentoring with team members; medical office hours for drop-in consults; and scholarships for attendance at the annual Washington State Hospice and Palliative Care Conference. An updated edition of the Palliative Care Handbook (2nd edition, 2023) offers each cohort a playbook to consider how they might continue developing palliative care in their community.

Defining community-based metrics is essential to quantify the impact of palliative care on cost, quality of care, and patient and family satisfaction. The WRPCI is working with the Washington State Department of Health to update data (results pending). Success will, in part, be measured by assessing consult numbers and advanced care planning completion.

A face-to-face listening tour with representative communities from cohorts one to three provided data for planning 2024 and beyond. Consistent themes included: requests for additional assistance in developing creative approaches for sustainably funding community palliative efforts; ongoing education opportunities, and initiative responses framed around the limited time that participants have to devote to palliative care efforts amidst expanding workloads.

Feasibility

The WRPCI was founded in late 2016 as a public-private partnership led by the rural health team at the Washington State Department of Health. While palliative care has grown in urban areas, particularly in hospitals, few have integrated the care into rural health systems or community settings. Even fewer services have worked upstream to identify and screen patients for services early in a serious illness trajectory. This innovative approach is among the first to use a synergistic combination of community-driven design, a learning network of rural peer communities, services in multiple community settings, telehealth case consultation, and clinical telemedicine for palliative care integration.

The overarching goals of this initiative are to:

- Assist rural health systems and communities to integrate palliative care in multiple settings, to better serve patients with serious illness in rural communities
- Move upstream to serve patients with serious illness earlier in their illness
- Develop funding models for sustainable services working across eight states.

Initially, seven rural communities in Washington formed the first cohort. These communities were selected for their champions and early adopters, low populations, and higher percentages of older adults. A second and third cohort have since been developed using similar criteria.

The communities use a standardized screening tool to identify eligible patients in multiple community health care settings. The tool creates a composite score based on the degree of illness, comorbid conditions, function, psychosocial factors, degree of symptom control, and frequent utilization of the emergency department and hospital.

The Palliative Care: Rural Health Integration Advisory Team (PC-RHIAT) guides the initiative design and planning. Members represented 24 public and private organizations with rural health, palliative care and telemedicine expertise. The initiative was also supported by a multi-state project led by Stratis Health, the Quality Improvement Organization for Minnesota (MN). Stratis began rural palliative care work in 2008, helping two dozen MN rural communities sustain palliative care. The WA initiative was led by Pat Justis, Executive Director of the State Office of Rural Health at the Washington State Department of health. Since the inception of the program, the team has expanded to include Gregg Vandekieft, MD Medical Director, Deb Watson, RN, Nurse Coordinator, Mandy Latchaw, MBA, Portal management and project manager, Tammy Arndt, Telehealth Consultant, Adie Goldberg, PhD, LICSW, Telehealth Hybrid Model Coordinator.

A community engagement strategy brings together diverse organizations in each community. Community teams assess current assets and gaps for palliative care to develop an action plan with a revolving one-year timeframe. Communities target objectives such as initiating clinical screening, launching consultative services, public education, improved coordination, or access to non-medical supports such as home adaptations, meals, or transportation. Clinical and culture change strategies include health team skills training, change management technical assistance, facilitation, a gathering of evidence, clinical standard adoption, support for workflow design, a resource portal, and education series.

Initial financial resources are modest funding from multiple private and public sources totaling $266,000 in direct income with overlapping fiscal years for a three-year period from 2017-2020. In-kind contributions include leadership, project management, administrative support, and workgroup facilitation from the DOH Rural Health team. Four contracts and three members who participate through in-kind donations support the expert panel for telehealth case consultation.

Funding from the Commonwealth Fund and Cambia Foundation supported:

1. Expanding the cohort size from the seven original communities to 20, and expanding telehealth consultations to a larger cohort community and offering them more frequently
2. Providing mini-grants to each community to facilitate capacity-building to help the organizations establish and standardize clinical services; kick-start telemedicine; operationalize metrics and quality improvement plans; set up business practices to be self-sustaining over time; and join CAPC as members for training/learning opportunities

3. Funding time-limited project management staff to coordinate the provision of a framework of services to the cohort, including skills training, resources dissemination, peer exchange, mentoring, change management coaching, and technical assistance
4. Providing skills training for each cohort community health organization and scholarships to state Hospice and Palliative Care conference

Scalability

In 2022, the WRPCI was presented to the Oregon Forum on Aging with great interest. The following information was provided.

The Learning Action Network (LAN) model is not site-specific, and as one MD noted, while the WRPCI offers professional mentorship, each rural team holds a PhD in their community. The underlying assumptions for this model are that 1) every rural health care organization and community is best equipped to set its own goals and pace; 2) any progress is a success; 3) the initiative is intended to be supportive but not prescriptive; and 4) everyone teaches, and everyone learns. This model allows for diverse groups of caregivers, no matter their geographic location, to collaborate and share best practices. By leveraging the collective experience of all participants, providers will be able to enhance patient outcomes and build community buy-in. A learning network paired with flex programs can drive the development of care for the seriously ill in any community. As one palliative care rural RN noted, “Cancer doesn’t happen to a patient; it happens to the community.”

The education telehealth model is a transferable process focusing on a telehealth-enhanced palliative intervention using videoconferencing for case-based learning, which can improve rural health care providers’ ability to manage more complex cases. The intervention reinforces evidence-based practice and models an interdisciplinary approach to care. The design includes a two-level approach, targeting both patients and providers. This study constitutes translational research, as it explores telehealth delivery of an intervention and its integration into standard care. Given its proven success within Washington State, palliative care case consultation delivered via telehealth can provide a feasible, replicable intervention that is empirically based, cost-effective, and reproducible across the nation. We strongly recommend attempting to build a state-wide palliative care initiative.

Equity

At its core, this initiative is a DEI response. The delivery of quality health care in rural communities is an equity issue and one of the initiative cohort members reminded us that most people live in rural communities not as a luxury but as an economic necessity, and frequently a multi-generational legacy. People are tied to the land. Per an executive summary published by UCSF and the Robert Wood Johnson Foundation (RWJF), "Rural communities have many cultural, organizational, and individual assets. Examples include strong civic bonds, community-based organizations and nonprofits, faith-based organizations, and educational institutions."

That same cohort member reminded us that rural residents deserve quality care and should not be penalized because of their location. The executive summary explored the delivery of health care based on place (urban versus rural) and within rural communities. "More than one in every seven Americans lives in a rural place. Rural residents, in general, are disadvantaged by place—facing geographic barriers to services, resources, and opportunities. Within the rural population, there also are wide disparities in health and mortality among socioeconomic groups. Worse health is consistently associated with lower education or income as compared to urban counterparts. Rural residents are disproportionately impacted by preventable cancers, severe maternal morbidity, and opioid misuse, and they are less likely to receive critical health care services such as cancer screenings and childbirth care."

Per the Rural Health Information (RHI) Hub, "Rural risk factors for health disparities include geographic isolation, lower socioeconomic status, higher rates of health risk behaviors, limited access to health care specialists" and subspecialists, and limited job opportunities. Rural residents are also less likely to have employer-provided health insurance coverage, and if they are poor, they often are not covered by Medicaid."

"Low-income people of color living in rural settings are multiply disadvantaged by place, race, and class," per the UCSF and RWJF executive summary. Plus, the RHI Hub states, "Adult American Indian and Alaska Native (AI/AN), non-Hispanic Black, and Hispanic adults living in rural areas self-reported higher rates of fair or poor health compared to non-Hispanic White adults. Additionally, rural non-Hispanic Black and AI/AN adults were more likely to report having multiple chronic health conditions than non-Hispanic white adults; rural non-Hispanic Black adults were most at risk for obesity and severe obesity; and rural AI/AN adults reported the most activity limitations due to physical, mental, and emotional problems."

Sustainability

As we look into the future for rural palliative care in Washington State, what will success look like? Patients and their families will be completing more advanced care plans in their own communities, where they feel comfortable with trusted local clinicians. Those clinicians will possess more skills to have goals of care conversations, deliver difficult news, and manage symptoms. As clinicians work together, overburdened physicians will be able to utilize trusted interdisciplinary team members in the delivery of primary palliative care and, when needed, be able to access telehealth case consults with trained specialists. Community members will increasingly have exposure to palliative care, and with that exposure, there will be a heightened awareness of its role and value.

What we have observed is that despite staffing changes, a national pandemic, and regional hospital program cutbacks, culture change within critical access hospitals is taking hold. Local advocates continue to carry the message forward. WRPCI staff are impressed with local problem-solving and care delivery with limited resources.

To help communities continue this effort, the portal contains multiple resources, including a webinar library providing information on: team development, assessing community telehealth capacity, legal issues at the heart of serious illness, and improving revenue streams for palliative services. The WRPCI Handbook includes a section on multiple sustainability strategies supporting communities in finding pathways to a fully sustainable palliative care service.

At the initiative level, we are addressing the retirement of the founding champion, Pat Justis, Executive Director of Washington State's Department of Health Rural Health since August 2014. A sustainability committee has been convened; succession planning is underway; visits are scheduled across the three cohorts during 2023-2024 with Pat and other Initiative team members; and grants are being developed to expand the Initiative within the state and across its borders.

The listening tour in 2023 identified validation for program elements already in place and requests for moving forward. These meetings highlighted the Initiative's commitment to a cycle that continues to hear from our stakeholders in developing offerings that address community concerns.

Advocacy efforts at the state level for palliative care support work in tandem with the cohorts. Currently, we are addressing fiscal issues by working with state lobbyists to include a bill requiring private insurers to provide a standardized palliative care benefit.

By highlighting the impact of palliative care through testimonials, data, and case studies, the initiative has been able to generate enthusiasm, build trust, and gain support. Having the right champions in place ensures that the WRPCI has dedicated individuals working together to drive change, build support, and advocate for improved palliative care in rural communities and at the state legislative level.

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About the Challenge

The John A. Hartford Foundation Tipping Point Challenge is a national competition to catalyze the spread of skills, ideas, and solutions that will improve health care delivery for all people living with a serious illness. It is sponsored by the Center to Advance Palliative Care and The John A. Hartford Foundation.

For more information, visit tippingpointchallenge.capc.org.