Toolkit for the Creation of a Rural Palliative Care Network

CLINICAL
SCHOLARS

A Robert Wood Johnson Foundation program

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ABOUT

This toolkit can be used as a resource for individuals and organizations interested in the development of palliative care services in rural areas.

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Executive Summary

OKANOGAN
PALLIATIVE
CARE

Our team is working to improve the quality of life of patients with life-limiting chronic disease in a frontier area of North Central Washington State.

Okanogan County, Washington is a huge, sparsely populated, poverty-stricken county with higher rates of chronic disease and worse health outcomes compared to Washington State and the U.S. The county is 5,281 square miles yet only has a population of 41,742. Residents of Okanogan County who are chronically ill, elderly and/or experiencing poverty suffer disproportionately and have higher mortality compared to the rest of the state and the country, and this is magnified by the rural nature of the county and the fragmented medical system. County residents who identify as Latinx or Native American face additional challenges, including linguistic, socioeconomic, and cultural barriers to care. All county residents have limited access to specialty care, and most patients who need specialty services have to travel 75-150 miles to the nearest metropolitan area. The COVID19 pandemic has exacerbated the pre-existing challenges that many county residents face in managing chronic illness, accessing healthcare and providing for themselves and their families.

Multidisciplinary, integrated palliative care has not been accessible in Okanogan County. There are multiple health service organizations spread across the County, but collaboration among these healthcare agencies has often been stymied by competitiveness, a lack of an electronic means of communication among settings and long distances separating would-be collaborators. To offer integrated palliative care across the diverse and fragmented care settings in the County, we need a new model of effective, multi-agency collaboration. Creating a sustainable palliative care service is a formidable challenge anywhere, but especially in a large, rural and under-resourced area such as Okanogan County. In rural areas there is a lack of trained palliative care providers and the small, under-resourced healthcare systems struggle to support palliative care services because the traditional fee-for-service reimbursement model does not cover the cost.

Our primary aim is to build palliative care services that are accessible to all residents of Okanogan County, with a special focus on the Latinx and Native American communities. To achieve this, we started the Okanogan Palliative Care Initiative with partners including local hospice, community clinics, hospitals and others. Together, we are working towards that aim in four main ways.

1 Build a specialized palliative care clinical service to support seriously ill patients and their primary care providers

2 Increase advance care planning by offering community education and workshops

3 Develop palliative care services for the unique challenges and cultural attributes of Latinx and Native American communities

4 Educate community providers including Emergency Medical Services (EMS) on primary palliative care

Planning

During multiple community meetings, we heard repeatedly that there were few services to support the chronically ill and their families. Healthcare professionals expressed concern about the utilization of emergency services to manage long-term health symptoms, minimal understanding of disease processes, lack of planning and support for disease decision making, and the poor quality of health expressed by this patient population, family and support systems. Physicians hoped to keep these patients out of the hospitals and emergency rooms for managing care of chronic and serious illness.

A connection to the Washington State Department of Health Palliative Care Project and conversations with a diverse group of healthcare locals in discussion about the health and welfare of our most vulnerable community members, led to the consideration of developing a palliative care team. Through a series of community listening events, we dug deeper into the needs of patients and their families, looked at the availability of services currently available, and then brought together 10 county healthcare service providers to explore mission and vision and initiate a SWOT analysis. Five key individuals expressed interest and commitment to work on this project. We developed Four Work Groups from the analysis, which we used to create a work team, apply for a HRSA development grant, and request inclusion in the Robert Wood Johnson Clinical Scholars program.

Project Team

Kevan Coffey, DNP: Clinical Lead, Family Health Center Integration Lead, and Clinical Staff

Justin Porter, EMT-P, RN: Emergency Service Integration and Clinical Staff

Sheila Brandenberg, RN, CHPN: Clinical Supervisor and HRSA Project Lead

Raleigh Bowden, MD: Service Director, DOH Partnership Lead, and Clinical Staff

Karen Jacobsen, LMHC: Advanced Care Planning, Clinical Staff, and Prepare Integration Project

Marilyn Baylor: Administrator

Sharmon Figenshaw: ARNP Clinical Staff

Leslie Tregellis, MD: Clinical Staff

Amy Haworth, Chaplain, RN, MSW: Volunteer Clinical Staff

Michelle Jerome, RN, ACP: Prepare Integration Project Lead

Key Skill Sets

Our initial team comprised a wealth of healthcare experience, although not in the same areas of expertise or specialty. We found the additional skills needed for this work were:

- Community service
- Compassion for those living with serious illness
- Drive to make a difference in our community
- Willingness to consider volunteering to develop a project

Funding

The Robert Wood Johnson Clinical Scholars Grant funding in 2019 kicked off the management team with funding to continue our primary employment, while developing team values, core work plan, personal leadership and business development skills. The Health Resources and Services Administration (HRSA) Planning grant was obtained in 2019 and supported the initiation of development of the team and project. Support via national HRSA conference, reporting requirements, and webinars also supported the growth of the project. The HRSA Implementation grant was awarded in 2021 and is to be completed in 2025. It supports the previous 2 year planning and creation of the Palliative Care Service, in addition to:

- Expanding work of integration into a key Healthcare system within Okanogan County
- Adding staff
- Expanding of business structure
- Developing of an increased network of partners

Billing for services was initiated in 2022. The model partners healthcare providers able to provide billing with supportive non-billing staff for improved communication, care coordination, flexibility to meet needs of patients via multiple methods of visit styles and connection.

Community Partnerships

Building partnerships within the community is essential for community-based work. Our initial environmental scan and needs assessment demonstrated the wealth of knowledge and expertise in local healthcare and community support systems, but also informed us regarding the gaps in the service throughout the county. Initially, we developed work groups around our first four program goals. We then canvassed local service organizations and provided opportunities to hear about Palliative care to consider how we could work together. This led to the development of a Consortium of agencies and organizations that demonstrated a desire to strengthen relationships, open channels of communication, and integrate palliative care into a wider base of service. Our initial core group was four county-wide services that serve patients with key palliative care needs. These were two county-wide primary clinics, a county-wide Home Health & Hospice organization, and one critical access hospital. The focus was initially on providing education on Palliative Care services and why a partnership was beneficial to the wider community. The benefits of community partnerships are the ability to expand support for all like services, program innovation, and the ability to work collaboratively to connect to the community and increase thought leadership with innovation, creativity, and resourcefulness. We have expanded our partnerships to include ten additional community and state-based partners working on the front line of healthcare in Okanogan county and Washington state.

We stay connected with frequent virtual or in-person meetings, often monthly, and telephone and email contact frequently. We provide consults on service, education, and information as requested by or for our partners. Our partnerships have led to new opportunities to support local small businesses, offer new and creative ways to join in community education, and support new grants or opportunities for our partners.

Project work

Palliative Care Services are delivered by an interdisciplinary team for patients with severe and chronic illnesses. The overall experience for patients is a wrap-around support service initiated by referrals from medical providers in Okanogan county.

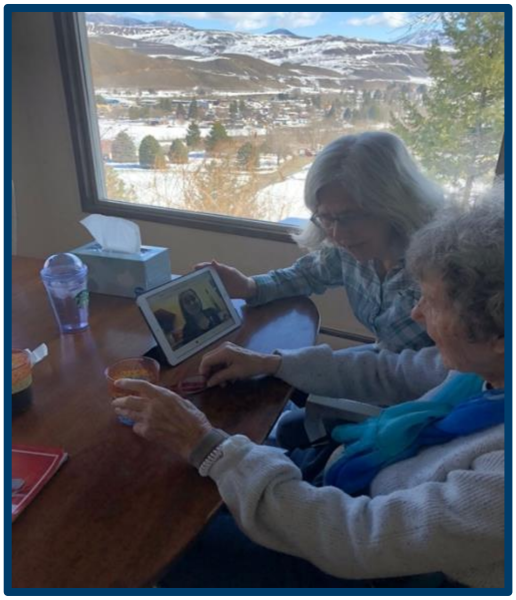
- Upon receiving referrals, the team engages in triage and needs assessment, ultimately assigning the appropriate team members to serve each individual.
- The team engages with patients in their homes or in clinics, in person, by phone and/or virtually.
- Palliative Care consists of needs assessments, inquiry, conversations about goals of care and identification of hopes/fears.
- The team acts in consultation with the Primary Care Provider/referring physician (PCP).
- Medication recommendations and care plans are communicated to the PCP, who can incorporate the consultation into their treatment.
- Advance Care Planning is provided, as well as spiritual care.
- Psychosocial issues are addressed and counseling is offered to the patient and the family.

Three Steps: Needs Assessment, Program Development, and Integration

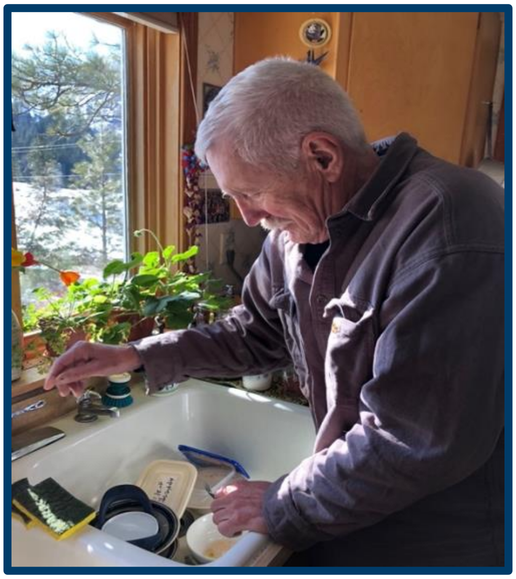
Needs Assessment	Key community providers identified gaps in services and support for people in our rural communities who suffer from chronic and serious illnesses. After conducting county-wide meetings with potential stakeholders and partners, we determined there is an overwhelming need for palliative care services. The critical-access hospitals in our area are small and underfunded, thus cannot afford to offer palliative care. Outreach included meeting with the Colville Tribe to learn about the Community Health Representative services, and their home-based support for elders of the Native community.
Program Development	The five team members began to develop the concept of Rural Palliative Care services through weekly meetings and met with community members and medical teams monthly. Early on, we recognized funding would be key to sustainability and consistency of service. The team submitted grant proposals and secured funding from RWJF and HRSA grants. The WA state rural healthcare initiative became an important “parent” agency which offered both guidance & financial support. Many hours of consultation with experts in the field were provided as well. Two team members acquired specialty certification in Palliative Care through University of Washington.
Integration of Services Within a System	Our Palliative Care service began gradually, one patient at a time, as we developed our workflow and documentation system. We offered services in homes and clinic settings, demonstrating our ability and intention to provide quality PC services. Family Health Centers (FHC), a Federally-Qualified Healthcare Center, continually partnered with us and supported our efforts. We ultimately joined with FHC as our umbrella organization, which affords us the support of their administration and structure. Now fully integrated, Okanogan Palliative Care is a service that is available to people with chronic and serious illness throughout our county.

Evaluation and dissemination

Our project monitoring is divided into six sections based on Performance Improvement Measure System (PIMS) developed by HRSA and non-PIMS measures. See Appendix for individual measures.



- The Clinical data helps ensure we are successfully enrolling the target population, will help us understand the underlying health reason patients are seeking PC, how their functional scores change over time (some may improve like functional level or sense of well-begin), whether they have tools to help set Goals of Care (e.g. Advanced Care Planning (ACP) tool or Physician Orders For Life-sustaining Therapy (POLST) which we want to corelate with Utilization data (e.g. reduced Emergency Room visits and hospitalization usage), and where they live so we can ensure we are serving the whole county and reasons for enrollment and discharge from PC.
- The Operational data helps us understand what kind of referrals we are getting and where they are coming from. We also assess the number of provider training and the competency achieved from the training. Finally, we measure the number of ACPs completed and entered into the electronic medical record and the competency patients achieve through the ACP process.



- Utilization metrics help us track number of patients served by the program), both by the Clinical Service and the ACP services. Importantly, we also track the impact of emergency room and hospital admissions/days prior to and periodically following enrollment in our program which will tie directly to our ability to affect costly interventions by our clinical service.
- Satisfaction measures are important as measures for quality improvement which help us improve out service and telemedicine as a way to deliver services. We are interested not only in the patient and caregiver experience but the experience of the Palliative Care and referring providers. We believe that our service will improve the experience for all. Particularly for primary care providers, who often have limited time in an office visit to provide the kinds of Palliative Care services that our clinical team is set up to provide.
- Tracking the number and changes in partnerships both at the Network level (we currently have 12 Network Partners) and at the Consortium Partnership level (we currently have 4 Consortium Partners). We will be looking to Consortium Partners to help build the infrastructure and assist with quality improvement of our program and to the Network Partners as referral sources and to also assist with quality improvement.
- Sustainability metrics outlined will help us track our income sources (both grant and patient care revenue) and will help us build a sustainable program.

Purpose of dissemination plan:

- Raise awareness of community-based palliative care
- Inform community partners and stakeholders
- Engage community in feedback and input
- Promote collaborative palliative care
- Serve as a model for development of palliative care in other rural communities

Audience for dissemination plan:

- Consortium and network partners
- Community members
- Education: Local and state college and health care programs
- Washington State Department of Health Palliative Care programs
- Policy makers: local, state and federal
- Robert Woods Johnson Clinical Scholars program
- Washington state Hospice and Palliative Care Association
- Center for Advanced Palliative Care
- Rural communities without palliative care

Forums and strategies for dissemination:

- Regular local meetings for partners
- Community outreach via education programs
- Decision Day events
- State Palliative Care events
- Press releases
- Marketing materials; brochures, fliers

Key Messages

- Palliative care focuses on quality of life and reducing suffering
- The multidisciplinary team is key to delivering quality care
- Partnership is key to successful programming
- Key metrics help us measure the effectiveness of our work and satisfaction of patients, their families and providers
- Current reimbursement mechanisms make it challenging to create a financially sustainable program, especially in rural areas
- Active strategies are needed to be inclusive of underserved communities

Lessons learned

- Everything takes longer than you think and being nimble is important, keeping our eye on the prize while incorporating the curve balls.
- Having a shared language (thanks to our mutual experience in Clinical Scholars) and understanding that we are always learning as individuals and collectively as a team has been very helpful. We've come to understand that we each make contributions in our own unique ways, and our collective work is stronger for it.
- Process influences progress. When we're feeling lost in the ambiguity and weeds of our wicked problem, we've learned to trust the process.

Challenges

The nature of our rural setting and huge geographic catchment area was one of our most significant challenges. The COVID pandemic compounded this ***isolation for both patients and providers***, since patients could not safely come to the clinic and home visits were similarly limited. However, COVID also led to the rapid expansion of telehealth as a reimbursable model of healthcare delivery. Telehealth became one of our most important solutions to the problems posed by our rural context. It allowed us to be much more creative in the ways we delivered services. Additionally, due to our rural setting, we lack specialists trained in palliative care (e.g. there are no board certified palliative care providers in the county). Therefore, we have been intentional about obtaining specialty training for our team members. The University of Washington's Palliative Care Graduate Certificate is now offered virtually, and we've had two team members complete it, with two more enrolling this coming year.

One of the biggest barriers to care for people with serious illness is the ***siloed-nature of our healthcare system***. Our county is no different, with multiple clinic systems and three critical access hospitals, none of which share a common EMR or billing system. When we came together as a team to form the Palliative Care Initiative, we were all working for different agencies, which posed significant challenges as we built our clinical service and started to see patients. With no common EMR or billing system and little administrative support, we could not have a sustainable service. One solution we employed was to integrate with Family Health Centers as our administrative home.

There is little understanding of palliative care among the public, patients and even local healthcare providers, on whom we rely for patient referrals. We employed multiple strategies to build ***collective community awareness*** of the value of palliative care. We developed a website, made and distributed our own educational videos, did presentations to multiple stakeholder groups, participated in community outreach events, and engaged individual providers in conversation about patient referrals. The use of social media is challenging because our population is elderly and many do not have internet access.

Successes

The largest accomplishment of this project is that we built a robust multidisciplinary palliative care ***clinical service*** that is serving patients across our county. Such a service is a rarity in rural areas, and, as far as we know, our service is the first palliative care clinical service run through a federally qualified community health center system. We now take referrals from partnering healthcare systems and operate as a specialty service across the county.

We were successful in securing ***additional grant funding*** beyond the funding from Clinical Scholars. In 2019 we were awarded a one-year planning grant from the Health Resources and Services Administration (HRSA). Once that grant period ended, we applied and were awarded a four-year HRSA grant, which will run through 2025.

Shifts in Thinking

We knew going into this that palliative care is about deeply caring for and building relationships with patients. We did not anticipate how much this was true for everything we touched in our project–***our relationships*** with each other and as a team, our relationships with partnering agencies, statewide initiatives, the graduate palliative care program, etc. We were courageous about embracing vulnerability in our interpersonal work together, and we found this ultimately to be one of our greatest strengths as a team.

Palliative care is time-intensive by nature and done best by an interprofessional team. However, in our fee-for-service healthcare system, only some members of the team can bill for services. We are increasingly embracing an enhanced ***team-based model of care***, enabling billing providers to see patients more efficiently while maintaining quality of care and patient and provider satisfaction. We are continually assessing how we can meet patients' needs (home visits to telehealth to clinic visit ratios) while maximizing ability to bill for services. The key to our team-based care is twice monthly meetings as an interdisciplinary team to discuss patient care and collaborate on treatment plans.

There is an ongoing conversation among palliative care professionals about the utility of ***Advance Care Planning*** (ACP) and how to maximize its impact on clinical outcomes. In our work, we initially focused on helping patients complete various ACP documents as a measure of success. But our thinking has shifted more to the importance of the conversation about end-of-life planning, encouraging patients to have these conversations with their loved ones and healthcare providers, rather than focusing on document completion as the measure of success.

Dale's Story

Our team got word that Dale was changing. Dale was starting to fall and his condition was clearly worsening. His family, his friends, and most importantly the caregiver at the nursing home thought that Dale needed something else, something more. The management at the nursing home put it to Dale bluntly:

"Dale, we're worried about you. Things are changing and we're short staffed. We think you need something else, something we're not providing. You need to find a new place to live. We want you to find a new place to live."

For Dale, this was really serious news. We found this out because we spent hours with Dale in the family meeting. Where we explored his hopes, his fears, and grief. Dale told us that while living in a nursing home wasn't what he pictured for himself, it was home and he found meaning there.

For how we helped Dale, watch Justin Porter's talk on YouTube: From Suffering to Wellbeing [3 Healthcare Shifts]

Recommendations

We recommend that you consume this toolkit like an owl consumes its meal. Digest it all and leave behind a pellet of stuff that doesn't nourish your work and situation. Start by endeavoring to understand how your community sees the problem. You can do this by traveling around your community and interviewing folks. When we did this, we asked people and healthcare professionals "what do you worry about with this patient population?" Our experience was one of surprise in finding that everyone saw it as important work and wanted to support it. You may too.

Surveying the community for people and organizations doing similar or adject work. Jump on their backs and use their infrastructure and resources. For example, we built our palliative care service from the ground up. We quickly saw that we didn't have the desire or bandwidth to build or purchase our own electronic medical record system. So, we partnered with a healthcare system that had one in operation (along with liability insurance, billing, buildings to name a few). By partnering with existing organizations, we created huge, short cuts in our work.

Our initial vibe was caution and calculation. We worried about over promising our product to our community. We mulled every decision over and didn't want to make a mistake. Our next step was to open and not worry so much about being perfect and managing every expectation in our community. We could see that we needed to launch, so that's what we did. We started seeing patients in their homes and in clinics, we hired staff, we trained community members in advance care planning, and continued to listen to stakeholders and our partners. This was a scary, but important step for us. Our recommendation is that eventually you may need to launch with discomfort.

Getting Started

- Do: Get clear on what success looks like
- Do: Build a team of diverse opinions but all committed to the same outcome
- Don't: Take on too much; need to stay focused on what matters.
- Do: Demonstrate care to your teammates, stakeholders, community members
- Don't' create something that the stakeholders haven't voiced a need or desire for
- Be Brave and jump in. Go for it! Great things do not happen without getting started; the world needs your Big Idea!

Best Practices

We used the evidence-based model of Community-based Palliative Care to develop our program. Over the past century, huge and costly hospital health systems have been built to which patients must come for their care. While this has served urban areas to a large extent, the most vulnerable and costly patients—the target population for palliative care services—do better when cared for in their own homes and communities, thus new models of care that orbit around the patient and family are emerging. Home-based palliative care is the future of quality medical care for the sickest and most complex patients and their families, says Diane Meier, MD, the Director of the Centers for Palliative Care.

One of the challenges in our county is that we have no major hospital (we have 3 small acute access hospitals) and limited long term care (LTC). Thus the majority of care in our community occurs in these agencies but to a larger extent in the two clinic systems (Family Health Centers and Confluence Health). Thus programs that run out of larger hospitals or large LTC or Home health agencies are simply not a part of the system in our county.

As a member of CAPC, we are fortunate to have CAPC to help guide our program structure, based on evidence-based models. Given that our target population is based in the largest rural county in the state of Washington, we have outlined in the Needs Assessment, that our county also contains a disproportionate number of frail, elderly, disadvantages people who are the very ones who will benefit from palliative care services. Data from a community-based palliative car study show that clinically relevant differences among settings of care, functional status, and symptom profiles between patients with various serious illnesses.

Research in rural palliative care remain sparse. However, approaches to telehealth, community / academic partnerships, and training rural health care professionals show promise. The authors conclude such success occurs not by bringing the patient to the urban experts, but by bringing palliative care expertise to the patient and/or ensuring that palliative care support becomes imbedded into the fabric of the rural community.

It will be important to establish a standard set of quality measures (metrics) that are useful for improving care and feasible for program evaluation. This recent published data comes from a study was conducted in five rural communities of Minnesota during 2013 by Stratis Health, a nonprofit organization that focuses on leading collaboration and innovation in health care quality and safety and our consultants with our WA State Department of Health Rural Health Collaborative of which we are a pilot site Evidence-based metrics are grouped into demographics, patient experience measures, hospital use data, and length of stay on the palliative care service.

We are fortunate to have as a consultant, Four Seasons Compassion for Life, who have published how they scaled their community-based palliative care model across 21 counties in rural North Carolina. Their success came from leveraging partner agencies across their state, one which we are already doing across our large County. We are using a similar model by starting with 3 sources of patients (both Clinic systems and one acute access hospital) and plan to build capacity one agency at a time.

How our model is different but builds upon evidence-based models:

- Many palliative care programs operate out of hospitals or home health agencies. Our program will focus on meeting patients where they reside, especially in the home or outpatient clinic which will serve two purposes. The first is that, even though we may identify patients in the inpatient setting, we will aim to provide a majority of their care in the home (either via house-call or telemedicine) because: 1) it saves the patient time, money and effort (especially for frail, elderly and poor) of traveling to a center, 2) our aim is to move upstream and provide strategies and care to reduce unnecessary emergency room/hospital visits, thus reducing cost, and 3) it allows our relatively limited staff (compared to the number of patients needing palliative care, to reduce travel time and thus see more patients. Second, because our county does not have a centralized system of care, we strive to work with patients from a variety of agencies, using one clinic system (Family Health Centers) as our administrative home.
- Metrics have been identified which we are expanding as part of this proposal. We will be building upon and expanding the metrics to include not only patient satisfaction but caregiver satisfaction. In addition, we believe a huge value to palliative care is to improve the quality of life of the PCP, given that management of complex patients in their short office visit is often extremely difficult and stressful.

Appendix

Baseline Metrics for Palliative Care Patients

	PIMS
Access to Care	1. Counties served 2. # in served in target population 3. # unique individuals 4. # via indirect services
Population Demographics	5. Race (LatinX, non-Latinx, Native American) 6. Age 7. Insurance (Medicaid, Medicare, Private, free care)
Network	8. Types 9. Number non-profit, for profit
Sustainability	10. Annual program revenue 11. Additional funding 12. Types of funding, source of funding 13. Ratio economic impact 14. Sustainability during and after project
	Non-PIMS (specific to our patient population)
Clinical	15. E-SAS, ECOG scores initial, day 30 at final 16. Diagnosis 17. Advanced Care Plan, POLST 18. DPOA 19. LOS PC 20. Reason D/C palliative care 21. Residence
Utilization	22. Emergency room, hospital visits and LOS 23. Health care costs 6 months prior to enrollment and at 2, 6 months
Operational	24. Primary Care referral source 25. Reason palliative care 26. Referrals
Satisfaction	27. Patient 28. Caregiver 29. PCP 30. Telehealth, ease of use, satisfaction