



Stratis Health Rural Palliative Care Impact Report

July 2016

Stratis Health, based in Bloomington, Minnesota, is a nonprofit organization that leads collaboration and innovation in health care quality and safety, and serves as a trusted expert in facilitating improvement for people and communities.

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Acknowledgements

UCare provided generous financial support for Stratis Health’s Minnesota palliative care work. Lyn Ceronsky, Fairview Health Services, provided subject matter expertise. Stratis Health’s national palliative care work was made possible by a grant from the National Rural Health Association.

Executive Summary

Stratis Health has pioneered processes for establishing and supporting palliative care services in rural communities. As often is the case in health care, the wealth of existing best practices were designed based on the large hospital model and did not translate well to work in smaller, rural communities. Recognizing this gap, Stratis Health led efforts to determine palliative care models that work in rural communities and to establish measures to understand how rural palliative care delivers value.

Background

In 2007, Stratis Health convened a diverse group of health care professionals and rural health experts to explore rural palliative care needs and opportunities. The panel identified a need to train clinical and non-clinical professionals in rural areas to better facilitate difficult conversations about goals of care discussions for those with serious illness and provide improved care for those with chronic diseases or in advanced illness.

“ We benefited from Stratis Health’s guidance and knowledge about what others have done. The support with goal setting really helped to move our system along.”

Bolstering this identified need, in November 2008, the National Quality Forum launched the National Priorities Partnership which highlighted “providing access to high quality palliative and end-of-life care” as one of six key strategies to reducing disease burden, patient harm, disparities in care, and wasteful use of health care resources.¹

In the ensuing years, Stratis Health supported 23 rural Minnesota communities, as well as three communities in other states, in exploring, developing, or expanding palliative care services for their community members.

What Is Palliative Care?

The goal of palliative care is to prevent and relieve suffering and support the best possible quality of life for patients of all ages and their families. Although closely linked, palliative care is not synonymous with hospice. In this country, hospice care is specifically defined by benefit coverage focused on people who are in the last stages of a terminal illness, while palliative care can be offered side by side with curative care at any point in the disease process. Palliative care is an approach to managing serious illness that centers on quality of life. Caring for the whole person is its cornerstone.

Why Focus on Rural Communities?

According to a 2011 report by the National Palliative Care Research Center, 89 percent of Minnesota’s large hospitals provided palliative care services, while only 37 percent of hospitals with fewer than 50 beds did.² Compounding this situation is the disproportionate and growing population of older adults in rural communities and the accompanying burden of chronic disease. Stratis Health also identified a number of strengths in rural communities that translate into unique opportunities for palliative care development, chief among them being the inter-connectedness and strong sense of community that often exist in rural communities.

Overview of Accomplishments

Since 2008, when Stratis Health began providing active support to communities through its rural palliative care work, 23 Minnesota communities participated in three program cohorts lasting roughly two years each.

- Cohort 1: 10 communities, 2008 to 2010
- Cohort 2: 6 communities, 2010 to 2012
- Cohort 3: 7 communities, 2012 to 2014

When analyzing the first two cohorts to assess the longer term impact, 11 of the 16 communities have developed and maintained palliative care programs, one is in the process of initiating a program after an incubation period, and an additional two have found ways to integrate palliative care principles into care delivery in the community even though they do not have palliative care programs *per se*. Of the seven communities that participated in the third cohort, four have developed palliative care programs. A seven-month national project in 2009 affirmed that rural communities are uniquely positioned to meet the challenges of providing palliative care through collaborative efforts.

Through this pioneering work, as leader and coordinator, Stratis Health learned a great deal about the challenges and opportunities facing rural communities that wish to establish a palliative care program, about techniques that are most helpful in supporting communities in that process, and about the factors that can help support success. Since launching the project, Stratis Health intentionally has adapted the process by which it does this work in response to what it has learned from communities.

“ We’re operating on the edge of capacity, with limited human resources. We’re waiting for reimbursement to catch up. We just fit palliative care in with what we are doing.”

Over time, the community capacity development component of the work has taken on greater significance and Stratis Health has come to see it as integral to the development of rural community-based palliative care services. Community capacity development is strengths-based, pragmatic, and inclusive, and requires collaborative leadership, broad participation, and the willingness and ability of a community to learn over time. Stratis Health has found that community capacity development is well suited to rural communities because they usually have a keen awareness of their collective strengths and weaknesses and a deep understanding of their culture, making them experts at identifying and tailoring solutions that best fit their unique situations.

From May 2012 to July 2013, Stratis Health led the Rural Palliative Care Measurement Pilot with five communities to identify and test a set of value-based measures for community-based palliative care services that are applicable for rural communities and useful in improving services. The communities collected and submitted operations, patient experience, and patient-level data to Stratis Health on a quarterly basis. Feedback and data from the pilot sites suggested that the pilot measures are relatively feasible to collect, are useful to palliative care programs, and capture relevant information for measuring quality.

Health Reform: An Opportunity for Palliative Care

The years-long debate that led to passage of the Affordable Care Act (ACA) focused on the question of how best to increase value in health care. Value can be increased by improving quality, reducing costs, or both. Palliative care holds great potential for increasing value by both improving quality and

reducing costs. It aligns well with efforts to redesign care delivery that are gaining momentum across the country. Health care systems and communities that have implemented palliative care may find themselves ahead of their peers as they adapt to the new value-based health care landscape.

Key Findings

Stratis Health has made a number of important findings related to developing, implementing and sustaining a rural, community-based palliative care program:

- 1) Health care organizations in rural communities can provide palliative care services effectively and the models for service delivery can and do vary widely.
- 2) For most rural communities, external resources and support are necessary to support community-based palliative care services.
- 3) Ongoing networking for learning and sharing is critical to program sustainability.
- 4) Defining community-based metrics is essential to quantify the impact of palliative care on cost, quality of care, and patient and family satisfaction.
- 5) More widespread reimbursement for palliative care services would contribute significantly to the sustainability of programs in rural communities.
- 6) Development of palliative care programs and services must align with other efforts to redesign care delivery and reimbursement to maximize efficiency for rural providers.

Introduction

In November 2008, in the context of the ongoing national debate about how best to address cost, quality, and access issues in the U.S. health care system, the National Quality Forum (NQF) launched the National Priorities Partnership. At that time, the Partnership was a collaborative effort of 28 national organizations (now 52 partners) to identify a set of priorities and goals to help focus improvement efforts on “high-leverage areas”—those with the most potential in the near term to result in substantial improvements in health and health care—and, thus, accelerate fundamental change in our health care delivery system. Providing patients with life-limiting illness access to high quality palliative and end-of-life care was one of the six areas identified as a national priority that would reduce disease burden, patient harm, disparities in care, and wasteful use of health care resources.³

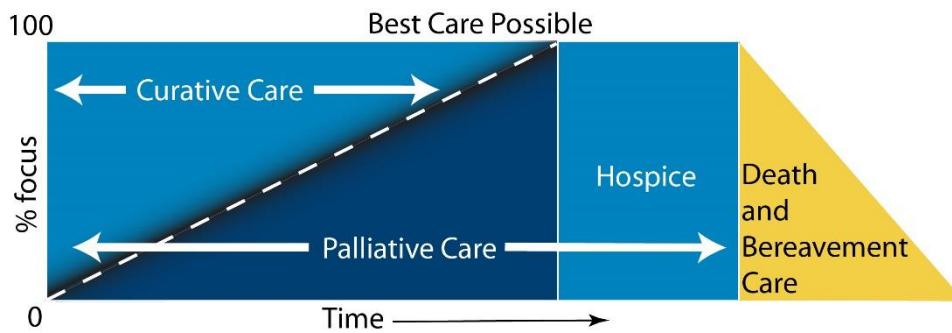
Even before NQF announced its prioritization of palliative and end-of-life care, Stratis Health had identified rural palliative care as an area of special need and opportunity. Stratis Health already had developed significant expertise in rural health quality improvement, having worked closely with Minnesota’s Office of Rural Health and Primary Care and other key rural health partners for several years. In 2007, Stratis Health, recognizing that its special expertise in rural health could bring a unique perspective to the emerging palliative care discussion, convened a diverse group of health care professionals and rural health experts to explore rural palliative care needs and opportunities. These experts concluded that there was a great need for training clinical and non-clinical professionals in rural areas to better facilitate difficult conversations about goals of care discussions for those with serious illness and provide improved care for those with chronic diseases or in advanced illness. In the ensuing years, Stratis Health has supported 23 rural Minnesota communities, as well as three

communities in other states, in exploring, developing, or expanding palliative care services for their community members.

What is Palliative Care?

According to the National Consensus Project for Quality Palliative Care, palliative care is both a philosophy of care and an organized program for delivering care. The goal of palliative care is to prevent and relieve suffering, and support the best possible quality of life for patients of all ages and their families. Palliative care can be provided along with curative treatment. In simple terms, palliative care is an approach to managing serious illness that centers on quality of life. Caring for the whole person is its cornerstone.

Figure 1. How Palliative Care Fits Within Care Delivery



Source: Milwaukee VA Medical Center, www.milwaukee.va.gov/services/Palliative_Care_home.asp, viewed 7/8/15

Palliative care customizes treatment to meet the needs of each person, seeking to relieve pain, anxiety, shortness of breath, fatigue, nausea, loss of appetite, and other symptoms. Practitioners of palliative care help patients and their families understand treatment options, and facilitate effective communication among health care professionals, patients, and family members. Emotional and spiritual support for the patient and family are hallmarks of palliative care. Palliative care may be offered in a variety of settings, including hospitals, long term care facilities, clinics, and private residences.

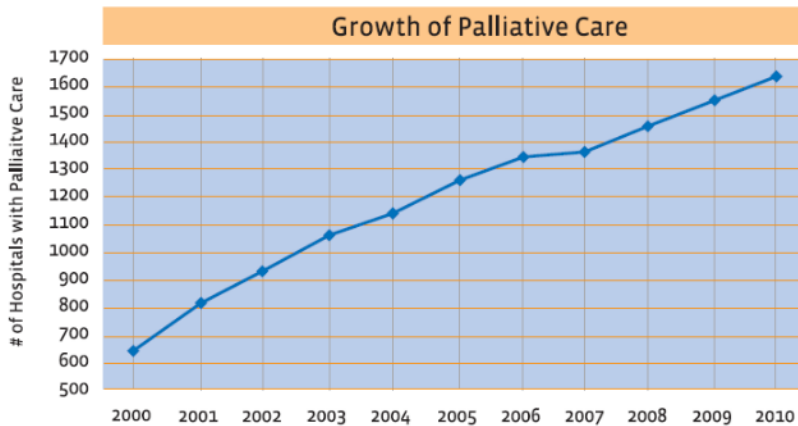
Palliative care can help keep patients out of the hospital and allow them to stay in their homes and live more comfortably with their illnesses. A number of studies have demonstrated that patients receiving palliative care have less pain, report increased satisfaction with provider communication, and use fewer health care resources than those who do not receive such care. Palliative care has come to be viewed as an approach that addresses both personal and family suffering as well as the cost of health care at the end of life and is increasingly recognized as an integral part of care for people with advanced illness. It is the fastest-growing medical subspecialty in the United States.⁴

Palliative care is not synonymous with hospice. In this country, hospice care is specifically for people who are in the last stages of a terminal illness, while palliative care can be offered side by side with curative care at any point in the disease process. The Medicare hospice benefit extends only to terminally ill patients whose doctor has certified they have six months or less to live, and does not cover curative treatment for the terminal illness.

Why Focus on Rural Communities?

Over the last 10 years, palliative care has been one of the fastest growing trends in health care. According to the Center to Advance Palliative Care (CAPC), the number of palliative care teams within hospital settings nationwide has increased approximately 148 percent in recent years, from more than 600 in 2000 to more than 1,600 today. This growth largely can be attributed to development of hospital based palliative care programs.

Figure 2. Growth of Palliative Care



From CAPC⁵, sources: 2002 to 2012 American Hospital Association Annual Hospital Survey for FY 2000 to 2010; and data from the CAPC National Palliative Care Registry.

Larger hospitals are more likely to have a palliative care team. More than 81 percent of hospitals with more than 300 beds have a team while less than one-quarter of those with 50 or fewer beds have one.

Table 1. Availability of Palliative Care by Hospital Size

Bed Size	# Teams in Hospitals	Total # of Hospitals by Bed Size	% of Teams by Bed Size
300+	639	727	87.9%
50 to 299	996	1,762	56.6%
Under 50	347	1,492	23.2%

From CAPC⁶, sources: FY2002-2009 AHA Annual Survey Databases. Chicago, IL: Health Forum, an American Hospital Association affiliate, 2010. National Palliative Care Registry: CAPC, as of July 2012.

According to a 2011 report by the National Palliative Care Research Center, Minnesota is one of seven states (plus the District of Columbia) that received a grade of “A” for having more than 80 percent of hospitals offering palliative care services. In Minnesota, 89 percent of hospitals with 50 beds or more reported providing access to palliative care services. Only 37 percent of facilities with fewer than 50 beds offer palliative care services, which is still higher than the national average of 23.2 percent.⁷

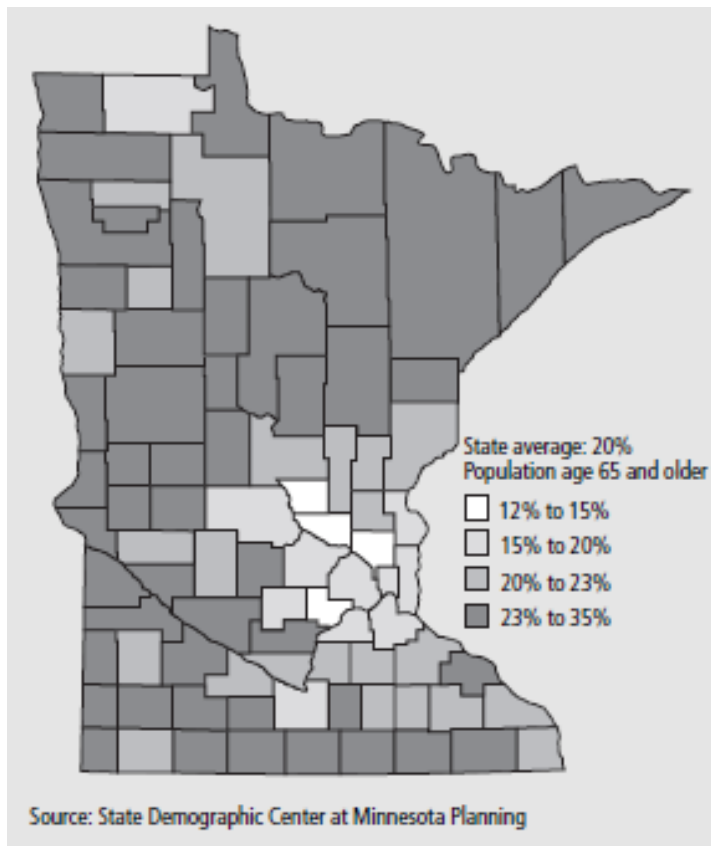
More than half of Minnesota’s 145 hospitals are designated as critical access hospitals (CAH), having 25 or fewer inpatient beds, and are less likely to have a palliative care program than other hospitals. To support financial viability for these low volume facilities, hospitals designated as critical access receive Medicare payment via a per diem cost-based reimbursement system so do not realize the same financial benefit for earlier discharge or less intense care than other hospitals. While this may not create a substantial disincentive for many of Minnesota’s 78 critical access hospitals to support

palliative care services, neither does it create an incentive. Rural residents have less access to palliative care services, and most rural communities do not have specific models of palliative care that are suitable to their size and circumstances.

Why is there a lack of palliative care in rural areas? Urban areas are more able to support hospital-based palliative care programs, as their patient volumes are large enough to allow staff to specialize in palliative medicine. The hospital-based palliative care team model, which is typically led by a physician or advanced practice nurse who may be trained or certified in palliative medicine, is difficult to implement in rural communities, as few physicians in those communities are trained in palliative medicine or have the patient volume to support specialization. In October 2012, eligibility requirements for physicians to become board-certified in this subspecialty were changed to require completion of a 12-month fellowship, making it even more difficult for physicians in rural communities to develop expertise in palliative care.⁸

To compound this situation, demographic data illustrate a disproportionate and growing population of older adults in rural communities. By 2025, the overall percentage of Minnesotans age 65 or older is expected to reach 20 percent, with only 15 counties, most of which are in or near the Twin Cities metropolitan area, having populations with less than 20 percent in that age range.⁹ People are generally living longer, often with multiple serious chronic conditions and an accompanying greater need for palliative care.

Figure 3. Elderly Will Be More than 1/5 of Most Counties' Populations by 2025



Source: State Demographic Center at Minnesota Planning¹⁰

In learning about the need for palliative care that exists in many rural communities, Stratis Health also identified a number of strengths that translate into unique opportunities, chief among them being the interconnectedness that often exists within rural communities. People work for the same employer and may have done so for many years. Their children often go to the same schools. They may attend the same places of worship. They may be coworkers by day and sit on the hospital board or city council together by night. The density of the social networks in rural communities often translates into people working together effectively, and this bodes well for community-based services like palliative care receiving strong community support, taking hold and flourishing. The interconnectedness of rural communities also supports a level of transparency and accountability that can be of particular benefit to patients and families, especially in cases of heightened patient vulnerability. Residents of many rural communities are accustomed to working with fewer resources than might be available in a larger community, and as a result, are often flexible and resourceful.

Stratis Health has concluded through its work with rural communities that the 38 preferred practices the NQF recommended to improve palliative and hospice care¹¹—such as end-of-life planning discussions, informing patients of the availability of spiritual care resources, and holding care conferences with the patient and family—are relevant and applicable in rural communities, in some cases echoing care processes that already exist. And while most small rural communities do not have the resources to employ the range of medical specialists that are part of a typical large-hospital palliative care team—such as a physician certified in palliative care—many rural communities do have partnership arrangements in place that allow them to tap specialty experts from larger communities on an as-needed basis.

Stratis Health and Rural Palliative Care: An Overview

To help address the need for palliative care services in rural areas, Stratis Health has worked with its partners for the past several years to develop and implement a series of community capacity-strengthening interventions to assist rural communities to establish or strengthen palliative care services. Since the initiative began, 23 Minnesota communities have participated in three Stratis Health-led program cohorts. A total of 150 organizations have been involved, and the size of the populations served has ranged from 1,200 to 200,000.¹² Stratis Health analyzed the first two cohorts to assess the longer term impact. Of the 16 communities that participated in the first two learning cohorts, 11 have developed and maintained palliative care programs, one is in the process of initiating a program after an incubation period, and an additional two have found creative ways to integrate palliative care principles into care delivery in the community, even though they do not yet have palliative care programs *per se*. Of the seven communities that participated in the third cohort, which wrapped up in late 2014, four have developed palliative care programs, with an additional one in the planning stages.

As leader and coordinator of this leading edge project, Stratis Health has learned a great deal about the challenges and opportunities facing rural communities that wish to establish a palliative care program, about techniques that are most helpful in supporting communities in that process, and about the factors that can help support success. Since launching the project with the first group of communities in the

fall of 2008, Stratis Health has adapted the process by which it does this work, in response to what it has learned along the way from communities.

From the outset of this work, Stratis Health has brought its unique combination of rural health, community capacity development, and health care quality improvement experience and expertise to bear in support of rural communities fostering palliative care. Over time, the community capacity development component of the work has taken on greater significance and Stratis Health has come to see it as integral to the development of rural community-based palliative care services.

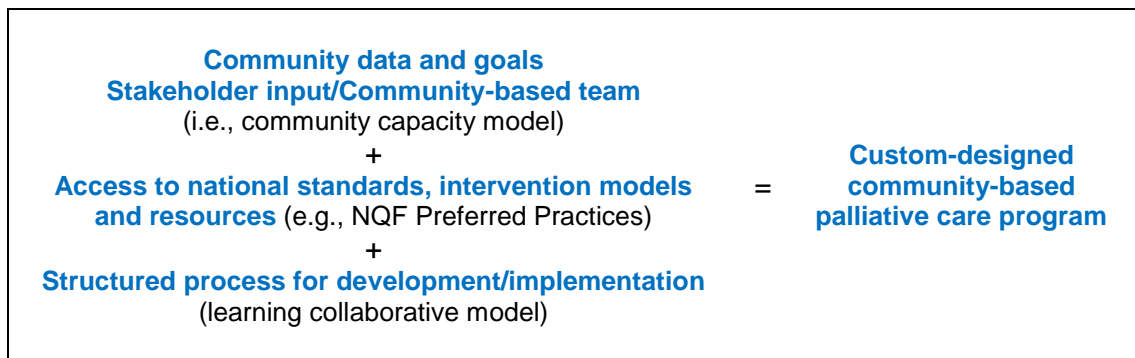
Palliative Care and Community Development: Stratis Health's Unique Approach

The theory underlying community capacity development guides community and public health initiatives as well as projects focused on social change. In defining community capacity development, the Centers for Disease Control (CDC) started with two concepts:

- The characteristics of communities that affect their ability to identify, mobilize, and address social and public health problems.
- The cultivation and use of transferable knowledge, skills, systems, and resources that affect community- and individual-level changes consistent with public health-related goals and objectives.¹³

The Aspen Institute adds: Community capacity is the combined influence of a community's commitment, resources and skills that can be deployed to build on community strengths and address community problems and opportunities.¹⁴

Figure 4. Formula for Community-based Palliative Care Program Development

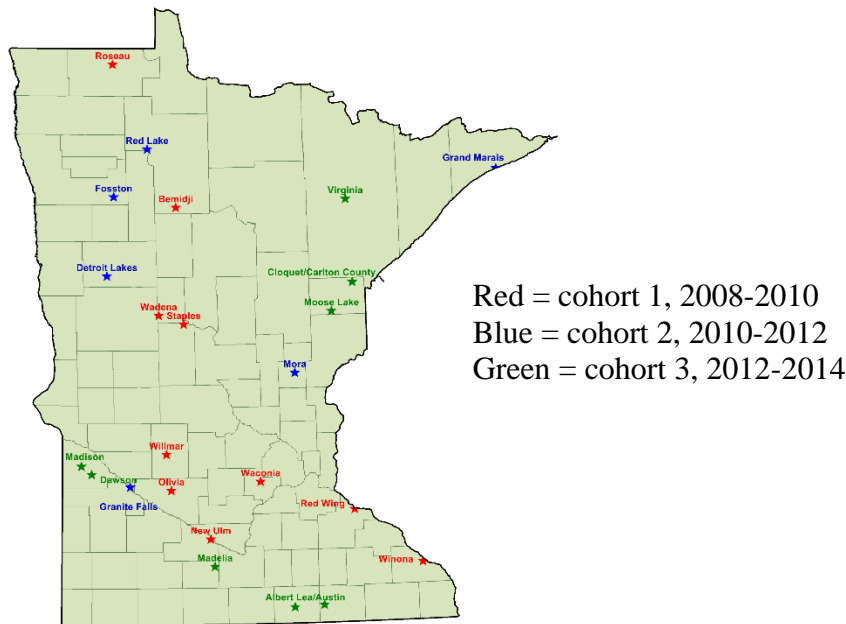


In practice, community capacity development is strengths-based, pragmatic, and inclusive. Change primarily comes about through enhancing existing capacities rather than creating something brand new. The approach requires collaborative leadership, broad participation, and the willingness and ability of a community to learn over time. Stratis Health has found that community capacity development is a process that is well suited to rural communities because those communities usually have a keen awareness of their strengths and weaknesses and a deep understanding of their culture, which combine to make rural communities expert at identifying and tailoring solutions that best fit their unique situation. In addition to community capacity development theory, Stratis Health's rural palliative care work has been informed by principles of the learning collaborative model originally developed by the Institute for Healthcare Improvement and by the National Quality Forum's *National Framework and Preferred Practices for Palliative and Hospice Care Quality*.

Project Components and Timeline

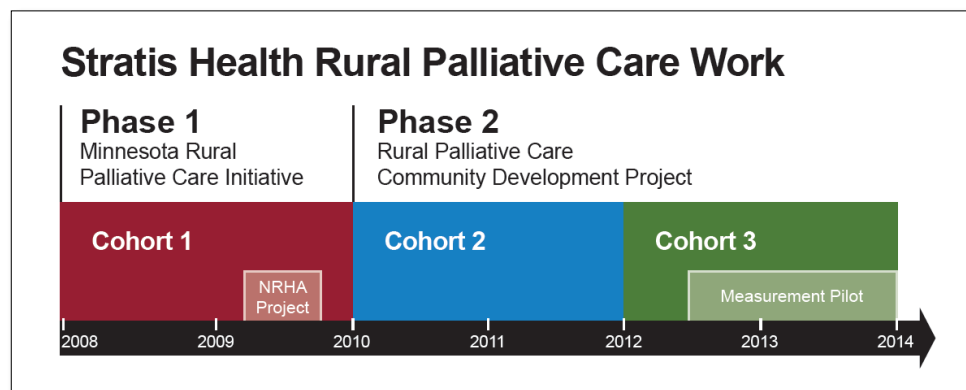
Since 2008, Stratis Health has assisted three groups of Minnesota communities (cohorts) to establish or expand palliative care services. As noted in Figure 3, the initial cohort which received active support from 2008 to 2010 included 10 communities: Bemidji, New Ulm, Olivia, Red Wing, Roseau, Staples, Waconia, Wadena, Willmar, and Winona. The second cohort, 2010 to 2012, included the six communities of Detroit Lakes, Fosston, Grand Marais, Granite Falls, Mora, and Red Lake. The third cohort, including the communities of Albert Lea/Austin, Cloquet/Carlton County, Dawson, Madelia, Madison, Moose Lake, and Virginia, received active support from 2012 to 2014.

Figure 5. Communities Participating in Stratis Health Rural Palliative Care Cohorts



To participate in any of the cohorts, a community was required to demonstrate that it had a team of individuals representing a range of organizations and disciplines willing to work on developing or enhancing palliative care services in their community. These teams could include nurses, physicians, social workers, chaplains, and others who have experience caring for people with advanced illness in a variety of settings. Over the years, participants have represented hospitals, home care organizations, hospice programs, long term care facilities, clinics, assisted living facilities, a college department of nursing, parish nurses, clergy, and public health agencies.

In addition to the Minnesota communities, Stratis Health provided support in 2009 to three rural communities outside the state through the National Rural Health Association’s palliative care technical assistance project. In 2013, in response to an identified need for appropriate quality measures, Stratis Health also facilitated a pilot project aimed at identifying rural-relevant measures for community-based palliative care.

Figure 6. Timeline of Stratis Health Rural Palliative Care Work

Stratis Health's Work in Rural Palliative Care: Phase 1, 2008-2010

Phase 1 of the project, known as the Minnesota Rural Palliative Care Initiative (MRPCI), used a number of mechanisms to bring multi-setting, multi-disciplinary teams from rural communities together, so that teams could learn from one another and take what they learned back to their communities. Thirty-five communities applied for the 10 slots Stratis Health had designated for the project. This strong show of interest led Stratis Health to recognize a broader need for this work. Stratis Health selected and invited communities to participate based on the strength of their applications, using criteria such as evidence of previous collaboration among proposed community partners, presence of a physician champion, and existence of stable leadership in the proposed lead organization. Phase 1 continued from fall 2008 through winter 2010, and was built on the three-part framework of the learning collaborative approach, the National Quality Forum preferred practices for palliative and hospice care, and community capacity development theory.

The goal of Phase 1 was for each of the 10 communities to design its own unique community-based palliative care program. The learning collaborative model provided the organizing framework for Phase 1, with Stratis Health convening the 10 community teams for three large in-person learning sessions over the course of 18 months. Between the learning sessions, Stratis Health provided webinar education sessions and individual team coaching calls and the communities worked to achieve their goals with technical support from the project team.

Starting in Phase 1, Stratis Health also built an online resource center intended to foster and support palliative care in rural communities. The center features operational, clinical, and educational resources, including sample order sets, action planning tools, rural-specific case studies, recorded training webinars, and links to other resources and organizations. The resource center can be accessed at www.stratishealth.org/palcare.

Phase 1 Results

Eighteen months into Phase 1, 6 of the initial 10 communities were enrolling patients in a palliative care program and providing them with interdisciplinary palliative care services. (One community had a program in place at the beginning of the initiative.) The other four developed and/or improved processes around aspects of palliative care such as advance care planning, implementation of common

order sets across care settings to support effective communication during patient transitions, and providing education on palliative care to health care professionals and others in their communities. The communities were providing palliative care in a variety of settings including home care, nursing homes, outpatient, inpatient hospital, and assisted living. Of the health care professionals involved in the project, 81 percent reported increased knowledge regarding effective care-goals discussions, and 73 percent reported increased knowledge regarding pain management.

Upon surveying the 10 communities again in 2014, Stratis Health learned that six of the communities continued to have palliative care programs, one is actively planning to launch a program in the near future, and an additional two remained committed to palliative care principles and had found ways to incorporate them into care delivery.

Three factors contributed significantly to the success of the Phase 1 initiative: 1) the commitment of the community team leads and team members, 2) the increasing local and national attention given to palliative care during the course of the project, and, 3) the structure and resources provided by Stratis Health and its partners.

Phase 1 confirmed the feasibility of building palliative care capacity in rural communities using a community capacity development framework, a learning collaborative, and the NQF preferred practices for palliative care. The unique nature of rural communities contributed to both successes and challenges. The successes included teams demonstrating a strong commitment to care for residents in their communities, an ability to leverage existing personal working relationships among clinicians in different settings, and comfort with their ability to try new approaches and achieve goals. Communities also invited involvement of social service agencies, faith communities, and programs serving seriously-ill patients to augment their clinical team capacity. Challenges specific to these rural communities included inability to recruit and support a palliative care specialist, the availability of a physician champion, unsuitability of traditional payment models, and the multiple responsibilities of staff.

The rural teams faced barriers similar to programs in other settings: lack of widespread understanding of palliative care and how it differs from hospice, the need to make the case with multiple stakeholders, and financial constraints. The community team approach also brought challenges. Team members, representing different settings and disciplines, did not always have prior experience working together or a clear understanding of the parameters of relationships among the participating organizations.

Major funding for Phase 1 was from UCare, with additional support from Minnesota's Office of Rural Health and Primary Care. More detailed discussion of the initiative can be found in the *Minnesota Rural Palliative Care Initiative Final Report* (June 10, 2011), which can be accessed online at http://www.stratishealth.org/documents/PC_Stratis_Health_MRPCI_Final_Report_2011_06.pdf

***“Start small...and begin”:* Lakewood Health System
*The Story of Palliative Care In and Around Staples, Minnesota***

Lakewood Health System serves a rural, central Minnesota population of about 38,000, including the 3,000 residents of Staples. Lakewood offers a range of services, including a 25-bed critical access hospital, a rural health clinic, long term care, home health, and hospice. Lakewood began practicing palliative care in 2005, when it launched its program out of the home care agency. In 2008, Stratis Health selected Lakewood to participate with the first group of communities in the Minnesota Rural Palliative Care Initiative. Since then, the program has continued to grow in scope and serves patients across settings, including long term care, home health, clinic, and hospital.

Lakewood's interdisciplinary team, which meets every two weeks to discuss and update plans of care, includes RN case managers, a social worker, a chaplain, a pharmacist, a physician certified in hospice and palliative medicine serving as medical director, spiritual volunteers, and a team coordinator. A unique feature of Lakewood's program is the team support they offer during and after clinic visits. A team member may accompany the patient and family to a doctor visit, then serve as “medical interpreter” after the visit, helping the patient and family to better understand what took place and answer any questions.

Based on its experience, Lakewood has identified four strategies that are essential to build and sustain a successful rural palliative care program: administrative buy-in, having a palliative care team and case manager, offering ongoing education for staff, and using the eight domains of palliative care, established by the National Consensus Project for Palliative Care,¹⁵ to guide care and program development.

Lakewood's palliative care program works closely with a range of partners in the community, including senior services, county financial services, public health, and veterans' services. Lakewood also collaborates with the University of Minnesota, which aimed to create and pilot exemplary interprofessional learning environments for health care students; the Department of Veterans Affairs, in the We Honor Veterans Program; and specialty providers from other communities. Team members connect with other communities engaged in palliative care through the networking and learning calls that Stratis Health facilitates several times a year.

Cindy Sauber, palliative care case manager at Lakewood, offers this advice to rural communities considering starting a palliative care program: “Discuss with your facility how palliative care can assist with coordination of care for your patients. Start small...make a goal of starting with 5 to 10 patients, and you may want to start with a specific diagnosis for the first patients...and begin.”

Stratis Health Leads National Rural Health Association Technical Assistance Project

Just as the MRPCI was beginning to take shape, Stratis Health was offered an opportunity to work on palliative care development with rural communities outside Minnesota as well. In 2009, the National Rural Health Association (NRHA) contracted with Stratis Health to provide technical assistance on community-oriented planning for palliative care to up to five rural communities across the country. From March through September of that year, Stratis Health worked with community teams in Franklin, North Carolina; Ruleville, Mississippi; and Valley City, North Dakota.

Each community team completed an initial needs assessment identifying the resources, needs, and opportunities in their community for palliative care processes. Stratis Health facilitated in-person day-long community capacity building sessions, incorporating education and action planning for palliative care with each community team. Formal technical assistance calls were held with each team twice during the project, and a final joint call was held for all three teams.

National Project Results and Recommendations

All three participating communities formed their own community-based team representing multiple care settings and developed an action plan related to palliative care processes. Two teams focused their efforts on advance directives, and the third community focused on building linkages between agencies that could provide services, and developing a “care captain” program with volunteers to support patients with complex care needs.

This project helped to reaffirm what Stratis Health had been learning through its work in rural health and palliative care in Minnesota—that rural communities are uniquely positioned to meet the challenges of providing palliative care through collaborative efforts. The project also demonstrated that a set process and timeline, access to palliative care program development expertise, and external facilitation to help initiate and develop community-based teams are important elements that can assist in further development of community-based palliative care in rural areas.

Funding for the NRHA technical assistance project was provided by the Health Resources and Services Administration – Office of Rural Health Policy, through the National Rural Health Association. More information about the project is available in the final report, which can be accessed at http://www.stratishealth.org/documents/NRHA_PC_Report_09-09.pdf

Stratis Health's Rural Minnesota Palliative Care Work: Phase 2, 2010-2014

Upon completion of the Minnesota Rural Palliative Care Initiative (Phase 1, Cohort 1), significant additional need for palliative care services in rural Minnesota was evident. Stratis Health and its partners decided to support another set of communities in a second phase of the project. This decision was based in part on the strong show of interest from rural communities when Phase 1 was launched and the over 30 communities that applied for the 10 available program slots. Phase 2 of the project, known as the Rural Palliative Care Community Development Project, was launched in 2010 and encompassed Cohorts 2 and 3. Cohort 2 included six communities and active Stratis Health technical assistance and support continued until 2012. Cohort 3, involving seven communities, received assistance from Stratis Health from 2012 to 2014.

Building on the success of the national project discussed earlier, the Rural Palliative Care Community Development Project placed a strong focus on the unique needs, resources, and plans of each individual community. Stratis Health provided more support for individual communities, including on-site education and working sessions, than it had during Phase 1. Less emphasis was placed on gathering all of the communities for large learning sessions, but other networking mechanisms were developed to complement the community development approach.

Similar to Phase 1 and the national project, teams from interested communities were asked to complete and submit an application to Stratis Health, a process which communities found useful in and of itself, as a way to begin to identify unmet needs, resources available in the community, and potential collaborative relationships. Stratis Health selected and invited communities to participate based on the strength of their applications, using criteria such as evidence of previous collaboration among proposed community partners, presence of a physician champion, and existence of stable leadership in the proposed lead organization. When the communities were on board, Stratis Health assisted each community team in identifying and clarifying its goals and assembling needed data. The teams sought stakeholder input from a broader swath of their communities as well as from team members themselves. Stratis Health facilitated the teams' access to national standards, intervention models and resources available through the NQF preferred practices for palliative and hospice care quality, and provided a structured process for each team's development and implementation process, including:

- Needs assessment/kick-off call
- Day-long visioning and planning workshops
- Coaching calls/individual technical assistance
- Community mentoring
- Tri-annual to quarterly educational webinars/teleconference calls

Similar to Phase 1 (the MRPCI) the goal of Phase 2 or the Rural Palliative Care Community Development Project was for each community to custom design its own unique community-based palliative care program.

Results of Phase 2, Cohort 2, 2010-2012

Of the six communities that participated in the initial cohort in Phase 2, five launched palliative care programs and began to see patients while receiving Stratis Health assistance and support. All six of the communities implemented palliative care education, and saw an increase in the occurrence of advance care planning and improved care coordination. At the beginning and the conclusion of the cohort process, Stratis Health asked participants to assess their communities' level of expertise in a number of areas relevant to palliative care. When comparing the initial to the final assessment, respondents' ratings showed improvement for most topics, with the greatest improvement in pain management consultation and staff education on palliative care. Respondents also reported increased confidence that their communities' pain and symptom management needs were being met, and that care transition processes in place in the community met the needs of patients.

Respondents were asked to rate the level of knowledge about palliative care that various types of health care professionals in their communities possessed. Health professional classifications included medical, nursing, social work/chaplain, pharmacy, other clinical, and administration. The final

assessment showed all classifications having increased knowledge, with the largest increases reported for nursing, social work/chaplain, and administration.

At the beginning and end of the cohort process, participants were asked to select, from a list of seven options, the top three barriers to providing palliative care in their communities. Lack of clinician knowledge, community awareness and coordination of care between settings decreased in overall significance from the beginning to the end of the cohort process, while medical staff commitment/buy-in and reimbursement increased in significance.

“ Our 10 physicians and medical staff would like to see the program branch out beyond home health to be offered in clinics and nursing homes.”

In addition to formal surveys, Stratis Health conducted follow-up interviews with representatives of the Cohort 2 communities in October 2012. A recurring theme among participants was that barriers will always exist, yet the desire to support patient needs can result in creative ways to establish palliative care as a service.

“ We just fit palliative care in with what we are doing because we love it. It's a personal passion of the individuals involved in it.”

Stratis Health followed up with the Cohort 2 communities in 2014, and learned that five of the six communities continued to have palliative care programs at that time.

Results of Phase 2, Cohort 3, 2012-2014

Phase 2 continued with Cohort 3, launched in spring 2012. Of the seven communities participating in Cohort 3, four had developed palliative care programs and were seeing clients by the end of the first year. At the end of the second year, four communities had programs although one community with a program at the end of year one was put on hold due to lack of a palliative care physician and another community began offering services. A survey of the Cohort 3 communities indicated that palliative care was provided in the nursing home, hospital, and home care settings and that programs were measuring effectiveness by tracking pain scores, quality of life scores, symptom scores, and/or patient/family satisfaction. Most programs tracked three to four of these metrics. In addition, the majority of the programs implemented three of the following processes: consistent order sets among two or more settings, health care professional or community education, a process for goals of care discussions, and advance directives. Medical staff commitment/buy-in and coordination of care between providers/settings were identified as the top barriers to providing palliative care. The majority of the teams were satisfied with how well their team functioned, the progress they made in the project and with their participation in the Rural Palliative Care Community Development Project. Finally, all respondents felt that participation in the initiative was critical to their community's progress toward developing palliative care services and were willing to recommend the Rural Palliative Care Community Development Project to other rural communities.

Additional Phase 2 Program Features Enhance Communities' Experience

In addition to the customized support provided to individual communities, Phase 2 of Stratis Health's rural palliative care work incorporated several elements designed to enhance communities' experience and advance understanding and knowledge in the field of rural palliative care:

- *The Rural Palliative Care Networking Group*: intended to encourage communication and build linkages among rural communities interested or involved in providing palliative care services. The group meets tri-annually and is open to anyone interested in rural palliative care (not only former participants in a Stratis Health technical assistance cohort). The group offers an opportunity for participants to share best practices and lessons learned in implementing community-based palliative care. An educational component is included in every meeting with the topics varying depending on the participants' needs. Stratis Health staff members facilitate the meetings, which are offered in a flexible format allowing for either in-person or virtual participation. There are 150 individuals that have participated in the group, with 30-50 people generally participating at each networking meeting.
- Continued development of the *Rural Palliative Care Online Resource Center*: intended to foster and support palliative care in rural communities by providing operational, clinical and educational resources.
- *The Rural Palliative Care Measurement Pilot*: intended goal was to identify and test a set of value-based measures for community-based palliative care services that are applicable for rural communities and useful in improving services. Stratis Health invited active rural palliative care programs from across Minnesota to participate, and received responses from five programs: Lakewood Health System in Staples, Kanabec County Palliative Care Team in Mora, Essentia Health in Fosston, Fairview Lakes HomeCaring & Hospice in Wyoming, and Madison Lutheran Home & Madison Hospital Home Care in Madison. From May 2012 to July 2013, the five communities collected and submitted operations, patient experience, and patient-level data to Stratis Health on a quarterly basis.

Stratis Health convened a technical expert panel of national palliative care and rural health experts to help identify potential measures and provide input into the pilot design. Feedback and data from the pilot sites suggested that the pilot measures are relatively feasible to collect, are useful to palliative care programs, and capture relevant information for measuring quality.

For example:

- ✓ Patients and families reported high satisfaction with the programs. Of the 29 patients from the measures pilot who returned surveys, all felt that the degree to which the palliative care team focused on their pain control was always or usually good, all were always or usually satisfied with the competence of the palliative care team, all were always or usually satisfied with the concern the palliative care team showed for them, and all said they would always or usually recommend palliative care to others in need of such services.
- ✓ Although there were limitations to the accuracy and availability of utilization data across the participating programs, patients served through these programs appeared to have lower utilization when comparing the number of hospitalizations, hospital in-patient days, and emergency department visits before and after admission to the palliative care program.

- ✓ All the programs indicated high satisfaction with their participation in the pilot with several indicating that the project had been very useful in improving processes and in strengthening continued program development.

Based on their experience with the measurement pilot, Stratis Health concluded that additional testing with a broader group of community-based palliative care programs would help to increase understanding of the feasibility and usefulness of a standard set of measures addressing quality, patient experience, and cost.

The Long View: Community Impacts and Sustainability a Few Years Down the Road

In 2014, to learn more about the sustainability of palliative care programs in rural communities and their impacts after the passage of time, Stratis Health followed up with the communities that participated in Cohorts 1 and 2, which received Stratis Health support from 2008 to 2010 and from 2010 to 2012 respectively. From the two cohorts, 11 of the 16 communities had a program in place in 2014. Of the remaining five, one is actively preparing to launch a program in the near future, and an additional two have found creative ways to integrate palliative care principles into care delivery in their communities, even without a formal program in place.

Table 2. Cohorts 1 and 2 – Status of Palliative Care Services Among 16 Communities

Status	Number of Communities
Program in place	11
Actively preparing to launch a program	1
Found creative ways to integrate palliative care principles into care delivery	2
No specific plans for offering palliative services	2

The 2014 survey confirmed that each community's program is unique, but home health nearly always plays a key role. In some communities, services also are offered at the hospital, local clinics, or in long term care facilities. Regular interdisciplinary team meetings and ongoing staff education—both formal and informal—are common denominators for these communities. Having a physician champion is key. In one community, the palliative care medical director is not based locally, but rather at a corporate location in the Twin Cities. He meets weekly with the local interdisciplinary team via telephone and makes periodic face-to-face visits, but recognizes that a physician champion also is needed on-site in the community.

***“Be patient...things don’t happen overnight”
Palliative Care and the Red Lake Band of Chippewa Indians***

The palliative care program of Red Lake Hospital serves the Red Lake Band of Chippewa Indians—11,275 members, approximately 6,500 of whom live on the Red Lake Indian Reservation. The program was launched after an interdisciplinary team attended a training at Mayo Clinic in 2009. Initially, the team included a physician who specialized in palliative medicine; hospital, clinic and community nurses; and a pharmacist, social worker, spiritual advisor, and community member. The departure of the palliative care physician precipitated a program restructuring. A geriatric nurse practitioner stepped into the leadership role, but then also left. The team developed a new action plan and hoped to get all the local providers—an internist, pediatricians, family practice physicians, nurse practitioners, and a psychiatrist—to buy in.

Mary Ann Cook, director of nursing at Red Lake Hospital, says the initial action plan developed with Stratis Health’s support kept the team focused through the first transition. They subsequently developed a new plan, screening tools, and nursing assessments, expanded the POLST form, and did extensive staff training.

The interdisciplinary team, which meets weekly, includes hospital, community health, and nursing home nurses, a pharmacist, a social worker and a parish nurse. The team’s spiritual advisor, a traditional healer, passed away.

At one point, they had 12 patients concurrently. Like most of those in Stratis Health’s initiative, the Red Lake program finds that lack of payment for palliative care is a barrier to implementation and sustainability. Lack of payment is directly related to another barrier, inadequate staffing for the community’s size.

Members of the Red Lake palliative care team strive to accommodate the cultural and religious diversity of the patient population. Mary Ann says, “Just because we’re all living here as a community doesn’t mean everyone’s beliefs are the same. Sometimes they might want a medicine man or might want to burn sage. We try to accommodate the patient’s preferences and we learn about those through the admission assessment.”

Mary Ann says assistance from Stratis Health has been invaluable. As a result of that support, team members are comfortable designing their own action plans, and have put other tools and resources they learned about through Stratis Health to work for their community. She advises other rural communities wishing to begin a palliative care program to be patient—things don’t happen overnight, to map out where you want to be with your program and how you want to get there, and to work with Stratis Health if possible.

Barriers Experienced by Communities

Although financial sustainability continues to be an issue for these communities, several do bill payers for palliative services. UCare is the payer mentioned most often. Communities also report having billed Blue Cross and Blue Shield of Minnesota and Veterans Affairs Health Care. One community representative says, “The VA gets it. Sometimes they will actually call and say, ‘This person is palliative.’” Home care agencies sometimes bear the biggest impact of limited payment sources. According to one respondent, “Two things in home care need to change to support palliative care—allowing payment for non-skilled services, and getting rid of the ‘homebound’ requirement. If those two things changed, we could start palliative care sooner and really save money in the system.”

“ There needs to be a way to support palliative care financially. Palliative care keeps people out of hospitals, it keeps them comfortable and happy.”

Some communities report that they are absorbing the costs of providing palliative care, but they can only do this to a point. One person says, “We would be able to provide care to additional clients if there was a payment source.”

In addition to billing and payment challenges, communities have experienced other types of barriers, including financial difficulties that caused priorities to change for key partners, licensure constraints, inadequate staffing levels, staff turnover, lack of a physician champion, and insufficient time for education and consultation.

Participant Insights on Benefits

All of the participants believe that palliative makes a difference in their patients’ quality of life. Citing these benefits:

- Patients are able to remain in their homes longer.
- Clients can more realistically evaluate their health care options.
- Clients often have more control over the course of their health care journey.
- Patients and families have less end-of-life stress.
- The transition to hospice is smoother, as the patients are more prepared.

“ While this service is not yet paid for across the board, there clearly is a benefit for the participants and long term cost savings for health care.”

Palliative care has the potential for health care cost savings. Participating communities saw reduced utilization of services, including fewer clinic visits, ER visits, and hospitalizations.

“Just do it!” Advice on Starting a Palliative Care Program

Many participants voiced that palliative care is a natural fit in rural communities. They believe that the culture and traditions of people who choose to live in a rural setting support person- and family-centered home and community based care. They offered this advice for starting a palliative care program in a rural community:

- Initiatives within a community must be based on the unique small town relationships which sustain it.
- Community buy-in is critical. Find a starting point which key health care providers and community members can agree on.

“ Health care professionals in the rural setting are very committed and connected to one another and to the community. This can make building an interdisciplinary program like palliative care easier than it might be in other places.”

- Pick one or two aspects of palliative care that will have broad support and are known to be effective in addressing suffering.
- Get people to tell their stories about suffering in the current system. This motivates individuals to make change within the complex health care system.
- Collaborate with as many community resources as you can to develop the program.
- Introduce the concept of palliative care to patients early in their disease trajectory so they can begin to consider their plans before they are in crisis.

***Palliative care philosophy “should be built into everything”
Roseau’s Journey***

At LifeCare Medical Center in Roseau, Jan Carr is director of social services, behavioral health, chronic disease management, and the discharge planning and swing bed program. Julie Pahlen is director of home care, hospice, and public health. Both passionate advocates for palliative care, they reflected on their community’s palliative care journey. “We’ve tried to incorporate palliative care philosophy into all of our work with home care clients. We took what we learned and applied it to chronic disease management. We’ve started to try to formalize palliative care. We want to embed it, not wait until the patient is almost ready for hospice and then start palliative care.”

Jan and Julie also emphasize the importance of keeping palliative care front and center through ongoing staff education. They started with formal education with “everyone who would listen.” They now incorporate palliative care as a topic in the annual education day LifeCare holds for nurses and aides. After education, the next step was creating policies, procedures, and guidelines. Stratis Health had introduced participating communities to the palliative care guideline created by the Institute for Clinical Systems Improvement, and the Roseau team adapted it to emphasize the nurse’s role. All new physicians receive LifeCare’s palliative care guideline when they come on board.

Jan and Julie feel strongly that there’s an ongoing need for the palliative care philosophy to be built into everything. For example, they want palliative care to become a priority for nurses working in the clinic, hospital, and nursing home, in the same way that assessing for pain is now accepted as the fifth vital sign. “If they notice things aren’t working as well as they should be, we want them to think of calling in palliative care for a consultation. We want this philosophy to be applied earlier on. This is aspirational for us.”

Jan and Julie summed up this way: “It’s an ongoing journey. We’re further down the road than we were when we started with Stratis Health but we haven’t arrived.”

Health Reform and Increasing Value: An Opportunity for Palliative Care

It has long been recognized that the cost of health care in the U.S. is increasing at an unsustainable rate. At the same time, the U.S. health care system underperforms on a number of qualitative dimensions. According to a recent report from the Commonwealth Fund,¹⁶ health care in the U.S. ranked last when compared to 10 other developed countries across measures of quality, access, efficiency, equity, and healthy lives. The years-long debate that led to passage of the Affordable Care Act (ACA) largely turned on the question of how best to increase value—understood as the relationship between quality, patient experience, and cost. Value can be increased by improving quality, reducing costs, or both. Palliative care practitioners and researchers understand that palliative care holds great potential for increasing value.

Dr. Diane Meier, director of The Center to Advance Palliative Care (CAPC), a national organization devoted to increasing the number and quality of palliative care programs in the United States, is a respected scholar in the field of palliative medicine. According to Dr. Meier, the case for palliative care improving value in health care is strong. She points to studies which show that the seriously ill and those with multiple chronic conditions and functional impairment make up about 10 percent of all patients in the U.S. but account for well over half of the nation's health care costs.¹⁷ Palliative care programs targeting this patient population in hospitals have been shown to both improve quality and reduce costs of care for the sickest and most complex patients.

Palliative care improves quality of care by improving physical and psychosocial symptoms, family caregiver well-being, bereavement outcomes, and patient, family and physician satisfaction. It reduces costs by promoting coordinated, communicated, and patient-centered care. Dr. Meier reports that the average per-patient per-admission savings as a result of hospital palliative care is \$2,659, resulting in an estimated savings of \$1.2 billion per year under the current penetration of services. She estimates that this figure would increase to approximately \$4 billion per year if capacity were expanded to meet the needs of hospital patients who would benefit from palliative care. Dr. Meier's numbers include only hospitals with more than 50 beds. They do not include most rural hospitals, or other community-based settings such as home care or long term care, where additional savings could potentially be realized.

Finally, palliative care may actually be associated with lengthening of life for some patient populations. According to the recently released Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, some evidence suggests that, on average, palliative care and hospice patients may live longer than similarly ill patients who do not receive such care.¹⁸ Researchers believe that factors such as reduced depression, fewer hospitalizations and high-risk medical interventions, and support for family caregivers, allowing patients to remain safely at home, may contribute to this outcome.¹⁹

Palliative care emphasizes team-based practice, a strong patient and family voice in decision making, and coordination of care across settings. Stratis Health's rural palliative care initiative has incorporated all of these features. Palliative care programs and services align well with the efforts to redesign care delivery that are gaining momentum across the country, many of them as a result of health care reform where the focus is on increasing value. For example, patient centered medical homes and reductions in

hospital readmissions are featured in the Affordable Care Act as mechanisms for increasing value, and palliative care has good potential to support both approaches as it's been shown to reduce utilization of high cost services, such as emergency department visits and hospitalizations. Health care systems and communities that have implemented palliative care may find themselves ahead of their peers as they adapt to the changing landscape of value based reimbursement.

Conclusion/Key Findings

Based on its experiences in rural palliative care, Stratis Health has made a number of important findings related to developing, implementing and sustaining a rural, community-based palliative care program.

- Rural communities can provide palliative care services effectively and the models for service delivery can and do vary widely. Most of the programs participants developed are based out of home care organizations or are led by a nurse or nurse practitioner based in a clinic or hospital. The services they provide are focused on patients receiving home care or outpatient services such as infusion therapy, or those in the hospital or nursing home. Communities vary in terms of the ways they deliver services, who serves on their interdisciplinary team, the patients they serve, and which staff member coordinates the program. Table 3 summarizes these variables.

Table 3. Variables in Program Structure

Methods of service delivery	Interdisciplinary team	Patient focus	Coordinating staff
Home visits	All team included	Hospice eligible but refused	Nurse practitioner
Clinic appointments	physicians, social work, nursing	Infusion therapy	Registered nurse
Nursing home visits	Other disciplines vary:	Home care with complex illness	Social worker
Inpatient consultation	Rehabilitation services	Inpatient consult when requested	Certified nurse specialist
Telephonic case management	Volunteers	Physician referred with complex illness	Advanced practice nurse
Volunteer support visits/services	Nurse practitioner	Nursing home residents – triggered by minimal data set (MDS) criteria	
	Chaplain		
	Pharmacy		
	Advanced practice nurse in psychiatry		

- For most rural communities, external resources and support are necessary to support community development of palliative care services.
- Ongoing networking for learning and sharing is critical to program sustainability and continuing progress.
- Defining community-based metrics is essential to quantify the impact on cost, quality, readmissions, and patient and family satisfaction.

- More widespread third party reimbursement for palliative care services, including visits by RNs, social workers, and chaplains, would make a significant contribution to the sustainability of programs in rural communities.
- Development of palliative care programs and services must align with other efforts to redesign care delivery to maximize efficiency for rural providers. Changes underway due to implementation of the Affordable Care Act, and other health reform efforts offer unique opportunities for this type of alignment and collaboration.

As our state and nation age, as awareness of the benefits of palliative care grows, and as pressure to improve value in health care continues, it seems evident that palliative care will move to a place of greater prominence in the care delivery system. The progress that Stratis Health and the rural communities who participated in this project have made toward understanding how palliative care can be delivered in rural areas—effectively, compassionately, and with deep respect for rural values and relationships—will likely play a key role in shaping palliative care in rural communities.

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Appendix A: Advisory Group Members

Minnesota Rural Palliative Care Initiative Advisory Committee

Barry Baines, UCare Minnesota/Celebrations of Life
Judith Bergh, Minnesota Department of Health
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Kathy Messerli, Minnesota HomeCare Association
Mark Papke-Larson, Sanford Bemidji Medical Center
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Kate Peterson, Stratis Health
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Cally Vinz, Institute for Clinical Systems Improvement
Lores Vlaminck, Lores Consulting
Karla Weng, Stratis Health
Rhonda Wiering, Avera Health
Ghita Worcester, UCare Minnesota

Appendix B: Initiative Participants

Minnesota Cohort 1, 2008-2010: 10 communities

- Bemidji
- New Ulm
- Olivia
- Red Wing
- Roseau
- Staples
- Waconia
- Wadena
- Willmar
- Winona

Minnesota Cohort 2, 2010-2012: 6 communities

- Detroit Lakes
- Fosston
- Grand Marais
- Granite Falls
- Mora
- Red Lake

Minnesota Cohort 3, 2012-2014: 7 communities

- Albert Lea/Austin
- Cloquet/Carlton County
- Dawson
- Madelia
- Madison
- Moose Lake
- Virginia

National Rural Health Association Technical Assistance Project: 2009, 3 communities

- Franklin, North Carolina
- Ruleville, Mississippi
- Valley City, North Dakota