

Leveraging Palliative Care in Rural Population Health Management

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The opportunity to better understand the impact of palliative care on overall population health and Triple Aim objectives has reinforced my commitment to the delivery of high quality healthcare for residents in rural communities, especially those with chronic life threatening conditions. I hope the knowledge I have gained about key program elements and implementation tactics can be used to support the expansion of rural community-based palliative care in my health system. I am grateful for the guidance of the faculty of the School of Business and Technology, particularly the Rural Healthcare program director Dr. David Swenson. I would also like to express my gratitude to my husband Brent, for his unwavering support as I pursued this degree. The sacrifices he made to accommodate my commitment to this program are greatly appreciated and will not be forgotten.

Abstract

Healthcare spending in the United States far exceeds that of other developed countries, but overall health outcomes are poorer. A small subset of the population with serious chronic medical conditions accounts for a disproportionate share of healthcare spending (Meier, 2011). Moreover, most deaths are attributable to complications from chronic conditions (Artnak, McGraw, & Stanley, 2011). Palliative care has been identified as an approach that can significantly improve healthcare quality (Meier, 2011) but expansion of these services has been limited to larger communities (McKinley, Shearer, & Weng, 2016). Rural populations are demographically older, poorer, and sicker than their urban counterparts, with a greater prevalence of chronic conditions (Artnak, McGraw, & Stanley, 2011). Though healthcare organizations in rural communities see the benefits of establishing palliative care to address this disparity, they often lack the resources necessary to institute a traditional program. Community based palliative care programs offer a viable alternative. While models vary widely, they share several characteristics, including a focus on home-based care delivery, multi-disciplinary care coordination, connection to palliative care specialists for complex cases, robust community outreach and provider education, and integrated advance care planning tools. A formal evaluation and implementation plan, such as the logic model presented in this paper, will aid the development of a program most suited to the unique needs of the rural community.

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Leveraging Palliative Care in Rural Population Health Management

Purpose

This paper will discuss the history of palliative care and how it can play a vital role in the improvement of overall population health and reduction in healthcare spending. It will also address the barriers to implementing palliative care programs and outline innovative solutions that could be applied in rural settings with limited resources. Finally, it will provide tactics and a sample logic model that may be used in the evaluation and implementation of a rural community-based palliative care program.

Need for Study

The expansion of palliative care services is one of the top six initiatives identified by the National Priorities Partnership in 2008 that, if addressed, would significantly improve the quality of healthcare in the United States (Meier, 2011). Palliative care is one of the fastest growing fields in healthcare, with a 138% increase in programs since 2000 (Ladha, Sharma, Batsis, Hanson, & Swetz, 2013). However, much of this expansion has occurred in larger communities. As of 2016, 78% of hospitals with over 50 beds have palliative services in place, while only 29% of smaller facilities have established these programs (McKinley, Shearer, & Weng, 2016). Rural populations are demographically older, poorer, and sicker than their urban counterparts (Artnak, McGraw, & Stanley, 2011). Many of these communities do not have adequate access to palliative care services, contributing to a significant disparity for the chronically ill in rural America.

Background: Health Care Spending and Outcomes

Healthcare spending in the United States is significantly higher than in other developed countries, and the nation's healthcare outcomes are worse, indicating a low return on investment

(Institute of Medicine [IOM], 2015). In 2013, the United States spent \$9,086 per capita, or 17.1% of its gross domestic product, on healthcare services, almost 50% higher than the next highest ranked high-income country (Squires & Anderson, 2015). Americans over the age of 65 also had the highest rate of two or more chronic conditions in 2014 at 68% (Squires & Anderson, 2015). Moreover, as of 2015 the United States did not rank in the top ten nations for life expectancy, lagging behind Switzerland, Japan, and even Singapore (World Health Organization [WHO], 2016a). A small percentage of patients with serious chronic medical conditions account for the majority of health care spending in the United States (Meier, 2011). Further, most deaths are attributable to complications from chronic conditions (Artnak, McGraw, & Stanley, 2011).

End of life healthcare has changed dramatically in the past two decades, but opportunities exist to improve this care and better incorporate individual preferences and beliefs (IOM, 2015). The WHO (2016b) defines palliative care as an approach to treatment that improves the quality of life of patients suffering from life-threatening illness by assessing and treating physical, psychosocial, and spiritual issues to prevent and relieve suffering. Studies have shown that this approach can positively impact patient outcomes, lead to higher patient and family satisfaction, and decrease overall costs of care (Meier, 2011; IOM, 2015; Temel, Greer, Muzikansky, Gallagher, Admane, Jackson, & ... Lynch, 2010). One study of patients with metastatic lung cancer found that the group with early palliative care intervention had a significantly longer survival rate and better quality of life than the control group despite receiving less aggressive treatment (Temel et al, 2010).

By 2020, there will be 88 million people older than age 65, double the levels of 2011. People are living longer with multiple chronic conditions and increasing their utilization of expensive healthcare services without a concomitant increase in quality of life (Artnak et al.,

2011). One in three rural residents have at least one chronic condition, and there is also a larger uninsured population than in urban areas. Further, less than 10% of physicians reside in rural areas, further limiting access to comprehensive care (Artnak et al, 2011). As America's population continues to age, the need for palliative interventions will become even more pronounced to address unmet demand and control increasing healthcare costs. Implementation of palliative care programs in rural areas will be an important tactic in improving healthcare for this vulnerable cohort.

Literature Review

A thorough review of existing literature on palliative care is necessary to better understand the topic. However, to understand the underpinnings of palliative care programs, it is important to examine its history, underlying drivers of program development, related supporting services, and the reimbursement landscape. It is also imperative to appreciate the unique health disparities, barriers, and advantages to implementing palliative care programs in rural communities. This foundation is the basis for developing innovative care models that can be applied in rural settings.

Triple Aim Objectives

Healthcare costs in the United States are growing at an alarming rate. According to the U.S. Department of Health and Human Services (2014), national health expenditures were 17.1% of gross domestic product in 2012, up from 12.1% in 1990. The Institute for Healthcare Improvement (IHI) defines the Triple Aim as “applying integrated approaches to simultaneously improve care, improve population health, and reduce costs per capita” (2016, Triple Aim for Populations section, para. 1). Health care value can be defined as the sum of care quality plus patient experience divided by the total cost of care, and the Triple Aim focuses on all three components (MacKinney, Mueller, Vaughn, & Zhu, 2014). One of the largest cost drivers of healthcare spending is end of life care. Over one quarter of lifetime Medicare spending is incurred in the last year of life (Donley & Danis, 2011) and this rate has remained consistent over the last forty years. The aging baby boomer generation is now becoming Medicare-eligible and life expectancies have increased, amplifying the strain on finite resources. Moreover, a large portion of high cost care is attributable to care that many patients do not want. Policy makers, insurers, and healthcare institutions must partner to form strategies to rein in costs while

providing high quality end of life care. The IHI (2016) emphasized the need to focus on high-risk, high-cost populations in order to make meaningful strides in the Triple Aim.

A recent white paper compiled by the American Hospital Association discusses appropriate use of medical resources. The authors proposed the following solution:

Use medical resources appropriately. By reducing the utilization of non-beneficial care – care that increases costs without a concomitant increase in value – we can have a delivery system that achieves the Triple Aim...improved health, a quality patient experience, and lowered costs. (Combes & Arespachoga, 2013, p. 1)

It is a disturbing reality that over 20% of Americans struggle to pay for required healthcare. This figure increases to over 30% for individuals with chronic illness (Donley & Danis, 2011). These statistics underscore the need for organizations to create multidisciplinary programs to assist patients with end of life care decisions and coordinate their care.

Organizations can employ several strategies to enhance end of life care and control overall costs. First, they should establish a forum for honest discussion of resource allocation (Jennings & Morrissey, 2011). Facilities need to be transparent to the community and employees about cost, without promoting a perception of rationing. Second, they can encourage patients and their families to assume an active role in their care so they can make fully informed decisions based on the facts of their conditions (Jennings & Morrissey, 2011). Next, identify and provide training on specific tools and scripts to assist caregivers in leading meaningful conversations with their patients to establish customized care plans based on personal beliefs and values (Jennings & Morrissey, 2011). Finally, they must develop a monitoring mechanism to measure their progress and identify areas where they can improve processes and results (Jennings & Morrissey, 2011).

History of Hospice and Palliative Care

The three main palliative care delivery models in the United States are hospital palliative care, community-based palliative care, and hospice (Aldridge, Hasselaar, Garralda, van der Eerden, Stevenson, McKendrick, & ... Meier, 2016). While most European countries use the terms hospice and palliative care interchangeably, they are considered two distinct services in the United States. Hospice care first became widespread in the United States in the 1970s, and focuses on multidisciplinary comfort care rather than curative treatment (Harrison & Connor, 2016). In 1982, Medicare Hospice Benefit (MHB) set criteria of a six month prognosis if the disease runs its normal course (IOM, 2015). Hospice care increased over 40% between 2000 and 2009, but it generally continues to be utilized only after repeated lengthy hospital stays, often in the costly intensive care unit (Giovanni, 2012). Over 85% of patients receive palliative care through the MHB, which currently will only reimburse for these services if the patient meets these criteria and foregoes curative treatment (Harrison & Connor, 2016). Patients tend to enroll in hospice care just weeks or days before death, which prevents them from fully taking advantage of the services hospice can provide, including family support (Giovanni, 2012).

While hospice care is defined as palliative care for those at end of life, not all palliative care is hospice (Labson, Sacco, Weissman, Gornet, & Stuart, 2013). Palliative care does not have the constraints of hospice and is typically provided earlier in the disease process. It offers a more holistic treatment focusing on enhancing comfort and uses a multidisciplinary approach to align care planning with individual patient needs, beliefs, and cultures. Palliative care focuses on the care rather than the disease itself. It provides several benefits, including better control of symptoms, fewer hospitalizations, lower levels of anxiety and depression in patients, and improved support for caregivers (Harrison & Connor, 2016). Much of the appeal of palliative

care lies in its dual emphasis on providing support to help patients remain at home as long as possible and ensuring the care delivered agrees with personal values, goals, and informed preferences (IOM, 2015). Palliative care can be an important precursor to hospice, supporting patients whose advanced chronic conditions limit daily activities (National Association for Home Care & Hospice, 2015).

Early integration of palliative care services into disease management has the potential to improve quality outcomes for patients and reduce overall healthcare costs (Aldridge et al., 2016). Linking palliative care across the healthcare continuum and integrating community and public health into the care plan are also opportunities to support improved delivery of these services and enhance patient quality and satisfaction (IOM, 2015).

Types of Palliative Care Programs

Palliative care can be provided in any care setting that has been accredited or certified to do so, but is most often seen in hospitals or clinics, skilled nursing facilities, and home health agencies (Labson et al., 2013). There are three main types of palliative care programs: hospital, outpatient, and community-based (Aldridge et al., 2016). Hospital palliative care programs most commonly consist of an inpatient consultation service based in a hospital (IOM, 2015). The palliative care consultant meets with patients and their families to develop treatment goals and identify potential barriers (IOM, 2015). Palliative care assessment tool is utilized to develop an integrated care plan that will be used throughout the course of treatment and holistically addresses patient needs (IOM, 2015).

Outpatient palliative care can be provided as an extension of a hospital-based program, in a clinic setting, or at long-term care facilities, and often focuses on pain management and quality improvement (IOM, 2015). Home health agencies are also starting to offer palliative care

services (Labson et al., 2013). Primary care providers (PCP's) are a critical part of outpatient palliative care programs as they are in the best position to coordinate care. They often know the patient best and understand family dynamics. They can effectively synchronize the multiple specialties, rapid changes in disease state, and integrate social and spiritual needs into the care plan. Patient-centered medical homes (PCMH) consist of multidisciplinary care teams that include the PCP, nursing, clinical pharmacy, social workers, and spiritual care (Klein, Laugesen, & Liu, 2013). The PCMH model has three characteristics that differentiate it from traditional primary care: integration of health care technology, patient-centered engagement in care, and a team-based approach (Klein, Laugesen, & Liu, 2013). Palliative care is an important subset of the PCMH model and supports the Triple Aim objectives of improved health, higher patient satisfaction, and an overall reduction in healthcare costs for this high-risk, high-cost population. It also helps alleviate the shortage of access to palliative care specialists, simplifies demands on patients and families, and reinforces existing positive relationships (IOM, 2015).

Community-based palliative care programs are emerging as another reaction to the shortage of access to palliative care services. Community-based palliative care includes a variety of delivery models to meet the needs of seriously ill patients outside of a hospital setting (Aldridge et al., 2016). These programs may be offered in clinics, long-term care facilities, and even patients' homes (McKinley, Shearer, & Weng, 2016). Care delivery may occur in conjunction with primary care coordination models and are often partnered with comprehensive advance care planning (ACP) initiatives. Community-based programs have been estimated to be very cost effective as well, with some estimating the monthly cost of all community-based, non-hospice palliative care services required for patients to achieve optimal independence of between \$800 and \$900 (McKinley, Shearer, & Weng, 2016).

Advanced Care Planning

ACP is an integral component to effective palliative care. It formally documents, in writing, the patient's wishes relating to specific medical interventions. The primary objective of ACP is to ensure patient wishes are honored. A byproduct of effective ACP is cost containment. An example is ventilation support. While this can be an effective and beneficial treatment, numerous patients, once informed of their disease and its probable progression, choose to avoid this intervention as it can be traumatic and uncomfortable, requires an expensive intensive care unit hospital stay, and likely will not result in recovery. Many prefer instead to spend their last days at home with loved ones (Stroebe & Moynihan, 2010). This illustrates a patient making a decision to obtain the greatest value of care based on his or her own beliefs.

ACP is a crucial process that should be initiated early, preferably at the time of chronic diagnosis, and is a key element to reducing unwanted burdens, ineffective interventions, and providing maximum value to the patient (Chen, Thorsteinsdottir, Cha, Hanson, Peterson, Rahman, & ... Takahashi, 2015). At first, it seems remiss to consider the term "value" in the context of end of life care. Patients' wellness and time cannot be significantly increased regardless of the quality of care provided. However, there are other measures to define value of care near death. These include the patient's preferred place of death, utilization of hospitalization, symptom control, family satisfaction, and decreased overall cost of care (Stroebe & Moynihan, 2010). It is ethically imperative to protect the dying, who are among the most vulnerable of our population, from both too little and too much treatment. This does not mean it needs to be a tragic decision. By implementing a patient-centered approach to end of life care planning, both quality and cost are enhanced (Jennings & Morrissey, 2011).

ACP first rose to prominence in the 1970s. Two legal documents became available for use in ACP. The first is durable power of attorney, which names a healthcare proxy representative to make decisions for the patient in the case of incapacitation. Advance directives, or living wills, go a step further and outline instructions regarding care (Kapp, 2002). They offer value to both patients and physicians. Patients have a standardized legal document to dictate their wishes regarding life sustaining treatments, typically to withhold or discontinue them. Physicians receive statutory immunity from malpractice if they comply with the document in good faith. This was necessary due to advancements in technology; newly available therapies made it difficult to discern between lifesaving treatments and prolonging of pain and death (Sabatino, 2010).

Nonetheless, there is substantial evidence that often the wishes outlined in advance directives are not honored. Critically ill patients frequently receive more aggressive treatment than what they had instructed (Kapp, 2010). This occurs for several reasons including ambiguity within the advance directive document, caregivers being unaware of or unable to locate the document in an emergent situation, and providers objecting to compliance with the document provisions based on their personal beliefs. This problem led to a third protocol, known as “do not” orders. It consists of a separate legal document within the patient medical record to withhold specific treatments, such as hospitalization, intubation, and the like. The most commonly used is the “do not resuscitate” (DNR) order (Kapp, 2010; Sabatino, 2010).

The most widely implemented model is Physician Orders for Life Sustaining Treatment, or POLST, a movement that originated in Oregon in the early 1990s. By 2004, a national organization was established, and today there are POLST programs in almost every state. The National POLST organization defines POLST as follows:

The National POLST Paradigm is an approach to end-of-life planning based on conversations between patients, loved ones, and health care professionals designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and honored. (2012, para. 1)

As they describe, the POLST document is geared for those patients who are critically ill or in the last year of life. Advance directives encompass a wide variety of “what if” scenarios, while POLST is based on a particular patient’s “when if” developments. In addition to instructions regarding resuscitation, it contains specifics on three levels of treatment: comfort care, limited intervention, or life-sustaining actions. There is also a section on administration of artificial nutrition and hydration. Comfort care is confined to treatment of symptoms to maximize relief of symptoms. It is one of the most commonly selected choices on the POLST document. Limited intervention is defined as treating potentially reversible medical conditions but not providing intubation or ventilator care, and generally avoids admission to the intensive care unit. Full treatment consists of providing whatever means necessary to attempt to sustain life. POLST utilizes the communications approach and works similar to the DNR order but extends it to a full range of care plans (Sabatino, 2010).

“The POLST paradigm enhances traditional advance directives by providing a more portable, comprehensive method of communicating a patient’s end of life preferences” (Matthews & Souther, 2013, p. 247). POLST has been widely recognized as providing positive outcomes. One of the goals of POLST is to ensure that the care plan is followed when a patient is transferred between various settings. It is incorporated into the electronic medical record and printed on bright pink paper that travels with the patient to help ensure the instructions are followed (Lynn, 2008). Several states have also established state-wide registries for POLST

documents so they are accessible via a toll-free number (Advance Care Planning, 2013). “A study of emergency medical technicians (EMT’s) experience of POLST found that when present POLST orders often changed the treatment provided and that EMT’s found it useful” (Schmidt, Zive, Fromme, Cook, & Tolle, 2014, pp. 480-481). The primary goal of POLST is that patient wishes are honored. By making the document readily available, the chances of appropriate follow-through are increased significantly. A study of the Program of All-Inclusive Care for the Elderly (PACE) patients with completed POLST forms had their wishes followed 98% of the time and did not receive unwanted treatments (Lee, Brummel-Smith, Meyer, Drew, & London, 2000).

Pertinent Legislation and Reimbursement Landscape

The most impactful legislation of recent years is the Patient Protection and Affordable Care Act (ACA) of 2010. Although only a few parts of the ACA deal with end of life care reform, multiple innovative efforts at state and local levels are improving care in this arena (Giovanni, 2012). These include reimbursement support of the PCMH care model, funding to support implementation of an integrated electronic medical record (EMR), and increased quality metric reporting requirements (Klein, Laugesen, & Liu, 2013). The increased focus on the Triple Aim has helped drive the increase in palliative care program development. Further, the ACA Medicaid expansion and subsidized insurance programs have reduced the number of uninsured patients who may have otherwise avoided care until very late into their disease process.

The ACA has also drastically increased the number of accountable care organizations (ACO’s) in the country. An ACO is defined as an entity that is held accountable by payors for the cost and quality of care provided to a specified population of patients (Shortell, Colla, Lewis, Fisher, Kessell, & Ramsay, 2015). As of 2015, there were more than seven hundred ACO’s in

the United States, about half of which were Medicare ACO's (Shortell et al.). While the evidence of whether ACO's help meet the goals of the Triple Aim is mixed, data does indicate a decrease in overall cost per beneficiary of dual eligible patient populations, largely due to reductions in acute care; those ACO's associated with the PCMH care model reported the highest quality and care management scores (Shortell et al., 2015). Unfortunately, since the ACA does not adequately address the provision of care for the terminally ill, this population's needs continue to be poorly addressed in the United States' healthcare system (Giovanni, 2012).

One indicator of a changing mindset is the Centers for Medicare and Medicaid Services (CMS) demonstration project for the MHB allowing participating organizations to provide hospice care to patients who are still pursuing curative treatment (Harrison & Connor, 2016). This project broadly increases access to the MHB. When the MHB was implemented in 1983, the average length of stay was 70 days, but by 2000, it had dropped to 48 days, at least partially due to federal regulation (Harrison & Connor, 2016). When a patient enrolls in the MHB, all health care services are charged to the program and reimbursement is managed through a capitated payment system based on a per-member per day rate regardless of specific services provided. Some larger hospice agencies have open patient access and allow for concurrent comfort and curative care because they can spread the financial risk of more expensive services across a larger patient population. However, many smaller organizations restrict hospice enrollment and exclude services such as chemotherapy or radiation (Harrison & Connor, 2016).

The Medicare Care Choices Model (MCCM) program was introduced in March 2014, soliciting applications from a small number of select hospice providers to participate in a five year demonstration project starting in January, 2016 (CMS, 2016). Eligible Medicare beneficiaries would be those eligible for hospice but not yet enrolled, and they would also need

to live at home and have diagnoses of advanced cancers, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), or HIV/AIDs; in return participating hospices would receive an additional \$400 per month for eligible beneficiaries enrolled for more than 15 days or \$200 per month for those enrolled less than 15 days (Harrison & Connor, 2016).

Given the restrictive criteria for participation in MCCM, it is estimated fewer than 15% of hospice patients will be eligible for enrollment, which may challenge participating providers with meeting the requirements of the program (Harrison & Connor, 2016). Further, the financial reimbursement of MHB and MCCM are misaligned. All hospice patients require a clinical assessment within three days of enrollment. If the patient assessment of a MCCM enrollee points to a short-length of stay, reimbursement under traditional MHB is advantageous, but the patient may see this as a means of giving up hope and be reluctant to transition to MHB (Harrison & Connor, 2016). While the MCCM is one of several efforts to address problems with MHB, it underscores the need for other types of palliative care service choices for this population. However, existing reimbursement models for pre-hospice palliative care do not support the provision of interdisciplinary care coordination, and new policy and payment mechanisms are needed to support the expansion of palliative programs (Harrison & Connor, 2016).

Legislation supporting ACP is also imperative to sustaining comprehensive palliative care programs. Palliative care is built on the foundation of patient choice based on individual beliefs and values, and without adequate documentation, their wishes often go unfulfilled by healthcare providers. The Patient Self Determination Act of 1990 sought to address problems with ACP tools and to support proactive completion of advance directives. It requires all organizations receiving Medicare and Medicaid payments to provide written materials to patients

regarding their rights and information on advance care directives, maintain written policies on ACP, document whether or not a patient has an executed advance directive, provide ongoing staff and community education, and comply with applicable state statutory guidelines (Sabatino, 2010). This legislation led to a more communication-centered approach to ACP to actively engage patients in their care, and spurred the creation of several community-based outreach programs, such as the Respecting Choices program developed by Gunderson Health in La Crosse, Wisconsin, Five Wishes, created by the Florida Commission on Aging with Dignity, and the POLST model originating in Oregon. These programs are a vital complement to community-based palliative care.

POLST is among the most widely adopted end-of-life ACP tool in the United States. The authority for POLST is governed by state regulations, and many states have laws that do not comply with the provisions of the document. For example, Minnesota statutes require that 911 not be called if a patient has chosen only comfort measures in his or her POLST. This precludes use of emergency services for unrelated care, such as broken bones (Advance Care Planning, 2013). As healthcare organizations continue to consolidate, their system footprints also often extend across state lines, further complicating adherence to POLST documents as state regulations between related facilities may differ. Finally, there is currently no third party reimbursement provision for POLST conversations (Sabatino, 2010). This results in uncompensated front-end costs to organizations that utilize POLST.

Rural Health Disparities

Rural communities are particularly challenged in healthcare delivery overall. Rural geography has also been shown to be a primary social determinant of health status (Lutfiyya, McCullough, Haller, Waring, Bianco, & Lipsky, 2012). Rural communities are often isolated by

distance from larger communities. Their populations tend to be older, sicker, and poorer than their urban counterparts. They also have higher levels of uninsured than more populous areas.

Geographic isolation of rural communities often contributes to limited access to healthcare, particularly specialty care, and this can leave patients without the resources they require to address their disease state. Less than 10% of providers practice in rural areas (Artnak et al, 2011). This rate is even lower for medical specialties such as oncology and cardiology. Many rural residents face long hours of travel to receive treatment at times when they are the most vulnerable. Long distance travel can also be financially prohibitive for caregivers, who may miss work and face high travel and lodging costs.

Barriers to Rural Palliative Care Programs

There are a number of barriers that impede implementation of palliative care programs in rural communities. These include limited resources, general perception and awareness of program details, inadequate training in geriatric and palliative care techniques, reimbursement limitations, and a fragmented healthcare system that lacks infrastructure to support coordinated multidisciplinary care (Aldridge et al. 2016).

Access to inpatient palliative care services varies by geography and hospital type, with hospitals in the South, for-profit and public hospitals, and sole community hospitals less likely to have programs (IOM, 2015). Small rural hospitals often lack the upfront resources required to create a comprehensive palliative care program. While many rural facilities are categorized as critical access hospitals (CAH's), those without this designation are even more challenged to find the financial support necessary to create palliative care programs.

Similar to hospice, patients often do not receive the full benefit of palliative services due to late referral (Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015). One major contributing

factor is the attitude toward healthcare in the United States. The increased spending trend is attributable to a “try everything” mentality that has permeated our culture over the last several decades as a result of the high rate of emerging technology and treatments (Combes & Arespachoga, 2013). Many patients and families see enrollment into palliative or hospice programs as a surrender to the illness. Providers may also avoid referral to palliative care to prevent patients from losing hope. For example, a survey of physicians with lung cancer patients found that 48% of providers had referred less than 25% of these patients to palliative care consultations, with the major reason being they did not want to cause alarm (Aldridge et al., 2016). Outreach and education efforts are necessary for the general population as well as for healthcare workers to spread awareness of how palliative services can support patient comfort and potentially even prolong life.

Providers are also often ill-equipped to initiate conversations about advanced care planning and end of life care (Aldridge et al., 2016). This is a gap in medical education across all disciplines outside of oncology and palliative specialties. Most care providers outside these specialties have received little to no education on palliative care and lacked confidence in addressing these situations (Aldridge et al., 2016). It is not realistic for small rural facilities to employ palliative specialists directly, so it is important to train PCP’s and other healthcare workers in basic palliative care techniques to enable them to support a comprehensive palliative care program. It is also essential to partner with larger organizations that have palliative specialists available for consultation to support more complex cases.

The increasing cultural diversity in the United States is another challenge to implementing effective palliative care programs. Failure to incorporate a population’s cultural norms into care planning can result in minority patients receiving disparately poorer quality

outcomes (Boucher, 2016). A review of 25 studies of end of life care indicated underutilization of advanced care planning and palliative care and increased rates of misaligned care and knowledge of treatment options in African Americans, Asians, and Hispanics in comparison to Whites (Boucher, 2016). Various cultural groups have shown to approach healthcare decisions differently. For example, Asians tend to employ family-based decision making, and African Americans and Hispanics are more likely to pursue aggressive treatments than other cultural groups (Boucher, 2016). Rural communities should consider specific cultural needs when establishing palliative care programs to improve rates of participation as well as patient and family satisfaction and outcomes.

Advantages of Rural Communities

Rural communities do have some advantages in establishing care coordination programs. First, healthcare providers in small communities often know patients and their families well. They also tend to have strong established relationships with community partners such as public health, schools and municipalities, non-profit and faith-based organizations, and other stakeholders. Community palliative care programs are often rooted in grassroots efforts, and the healthcare organization can serve as the integrator to combine efforts of multiple organizations into a comprehensive program. Rural hospitals are also more likely to receive supporting grant dollars to implement programs to enhance care delivery. As small CAH's affiliate or merge into larger health systems, they can be attractive as a way to leverage their Medicare cost-reimbursement status and small size as successful pilot program sites.

Solution - Specific Models and Tools

Hospital-based palliative care programs managed by a physician or advanced practice nurse are difficult to duplicate in rural communities, as few clinicians in small facilities have training or certification in palliative medicine (McKinley et al., 2016). However, there are a number of innovative palliative care models that could be successfully implemented in small rural settings. Those programs share several characteristics. First, they are community-based and rely on outpatient or home health coordination of care. Next, they garner broad community support through education and outreach to help change cultural norms around palliative care. They also rely on training primary care and other healthcare providers to handle the majority of cases, leaving only the most complex patient panel for palliative care specialists to manage, either through in-person or telehealth outreach. They have a strong continuing education component to empower healthcare generalists to better manage a complex end of life population. Finally, they are coupled with a comprehensive ACP model to firmly embed patients and families as active, informed participants in their care plans.

Stratis Health Minnesota Palliative Care Initiative

Between 2008 and 2014, Stratis Health supported the development of palliative care programs in 23 rural Minnesota communities; more than 150 organizations service communities with populations of 1,200 to 200,000 people were represented (McKinley, et al., 2016). These efforts resulted in the creation of fifteen new rural palliative care programs, while other organizations are integrating palliative care principles into their care delivery without creating a specific program. As of 2015, 45% of Minnesota facilities with fewer than 50 beds offered palliative care services compared to the national average of 29% (McKinley, et al., 2016). While the way services are provided varies widely, most programs are operated by home care

organizations or are led by nurse or nurse practitioner based in a clinic or hospital. Services are generally steered toward home-based or outpatient delivery models, such as home infusion therapy. Many organizations have also developed partnerships with larger communities to allow for access to specialists as needed.

The participating organizations view palliative care as a part of the healthcare continuum with earlier palliative intervention slowing the slope of patient health decline. FirstLight Health System in Mora, Minnesota, serves a five-county region with 34,000 began its community-based palliative care program in 2011. Like many other rural communities, much of its population is poor and has limited health literacy. Initially, patients with COPD and CHF were the primary referrals into its program. Today, any patient with an end-stage chronic disease may enroll, and the FirstLight program has an average daily census of 20 patients (McKinley, et al., 2016). Its palliative care team is led by a dyad of a social worker and nurse who coordinate with a network of home care agencies, skilled nursing facilities, spiritual caregivers, and volunteers, and also works with clinical pharmacy and other ancillary care providers for symptom management and pain control based on an individualized care plan developed collaboratively by the patient and care team. This cooperative effort has led to patients reporting their symptoms earlier and care team staff understanding their patients at a deep level, resulting in more successful disease management, reduced hospital admissions, and greater independence for program participants (McKinley et al., 2016).

Mayo Clinic Palliative Care Homebound Program

While Mayo Clinic has a global reputation of healthcare excellence and serves patients from all over the world, much of their service area includes small rural communities. Their Palliative Care Homebound Program (PCHP) in Rochester, Minnesota provides a home-visit

medical service focused on optimizing symptom management and maximizing quality of life in the months to years preceding hospice eligibility (Chen, et al., 2015). The program structure includes an interdisciplinary team involving registered nurses (RN's), nurse practitioners (NP's), geriatricians, palliative care consultants, with ready access to social services, pharmacists, and case management. One NP manages a panel of 20-25 high-acuity patients. One RN is shared between every two NP's and manages enrollment, phone triage and follow-up, medical scheduling and coordination with community-based organizations. A physician is assigned and attends a weekly one hour interdisciplinary team meeting and provides an in-person home visit twice annually on average. A key component to the program is consistent and frequent ACP, such as POLST, with evaluation of patient goals related to their chronic disease and its natural progression. A recent clinical study of 116 PCHP patients showed they had significantly lower rates of hospital admission, shorter lengths of stay when hospitalization was required, and a much higher prevalence of advance care directive documentation within the EMR (Chen, et al, 2015). The study shows that early palliative care intervention is associated with an improved ACP process throughout the continuum of the disease and suggests that reduced hospital admissions may be a result of properly understanding the patient's advance care directive (Chen et al, 2015).

Sharp's Transitions Model

Sharp HealthCare in San Diego, California developed Transitions, an innovative concurrent model of chronic disease care designed to address failures in traditional care pathways (Hoefer, Johnson, & Bender, 2013). The program is based on four evidence-based pillars: in-home medical consultation and care, ongoing evidence-based prognostication, caregiver support, and advanced care planning (Sharp HealthCare, 2016). While each of these

pillars has evidential support, combining these elements into a comprehensive chronic disease care model is relatively new. The program is meant to be a pre-hospice service, and utilizes a multidisciplinary team of professionals, with an RN the core care coordinator. Each RN manages a caseload of 30 to 35 patients. Care is organized into active and maintenance phases. During the active phase, patients receive between four and six weekly home visits from the RN to assess current needs, establish a care plan, and electronic medication profile. Follow up calls are completed between visits to address any changes in patient status with a goal of the patient receiving the majority of their care in the home. A preliminary evaluation of a group of patients with advanced heart failure showed a 50% decrease in acute care utilization after enrollment in the Transitions program (Hofer, et al., 2013). Further, 75% of the patient sample eventually transitioned into the hospice program, double the national rate of Medicare patients with the same condition. (Hofer, et al, 2013).

The program was developed specifically to be administered in the patient's home, but participants do not need to be homebound or meet the other requirements for the MHB. Home based interventions have been associated with improved quality of life, lower rates of hospital admissions, longer survival rates, and is more cost-effective than a clinic or hospital-based approach (Hofer, et al., 2013). The Transitions program focuses on providing patients and family education to foster a higher level of knowledge about their disease, shared goals of care, and improved compliance with the established care plan. Evidence-based prognostication provides accurate information on disease progression and life expectancy so patients can make informed decisions about their future care. It helps migrate patients and caregivers to a proactive care model technique focusing on the demands of each stage of disease. Palliative care physicians collaborate with PCP's and chronic care nurses to help identify when a patient is

demonstrating declining patterns and is at high risk of hospitalization. This supports providers and nurses without specialty palliative training learn how to manage chronically ill patients more effectively over time. ACP is used to formally document the process of discussion and feedback to ensure the care plan is consistent with patient goals, including increasing the probability that the patient will die at home as their preferred place of death (Hoefler, et al., 2013).

The last pillar of the Transitions program is caregiver support. Most chronically ill patients are reliant on family or friends to assist with maintenance care needs, and this can be burdensome and highly stressful for caregivers. Providing supportive care can contribute to a higher risk of physical and psychological health issues for the caregiver (Hoefler, et al., 2013). Transitions staff prioritize caregiver assessment and support as part of the overall program. Involving caregivers directly in education, advance care planning and preparation discussions has been shown to lead to increased satisfaction, higher feelings of preparedness, more acceptance of the role, and better health in this group (Hoefler, et al., 2013).

A number of other successful community-based palliative care programs target seniors, including Programs of All-Inclusive Care for the Elderly (PACE), Optimizing Advanced Complex Illness Support (OACIS), Sutter Health's Advanced Illness Management (AIM) program, and Palliative Access Through Care at Home (PATCH). Each of these models share several critical components, including holistic patient-centered care with a multi-disciplinary team led by an NP or RN, focus on outpatient or home-based interventions, provider, patient, and family education, realistic disease prognostication, and use of advance care planning tools.

Composite Rural Palliative Care Delivery Model

The decision to implement a palliative care program in a rural setting is an important step toward improving healthcare delivery and overall population health in the community. While each community is unique and programs will vary based on specific populations, the literature outlines several common components that should be incorporated into a community-based palliative care program (see Figure 1).

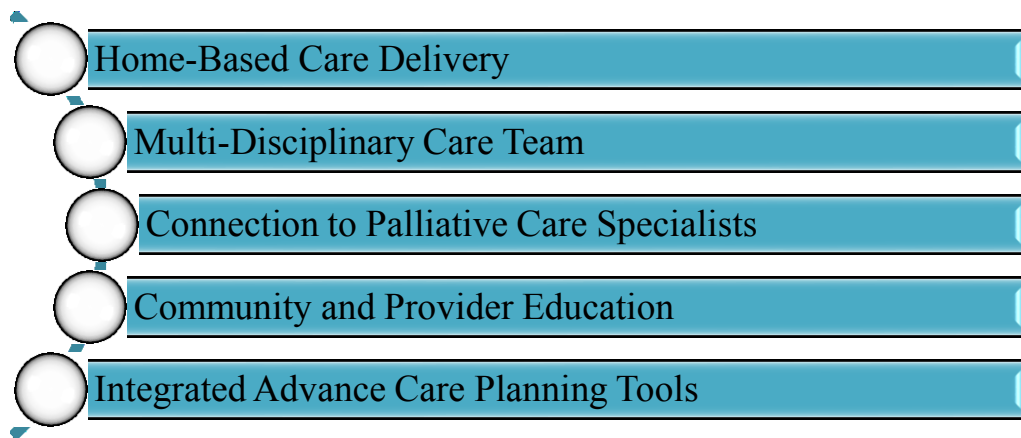


Figure 1. Elements of a successful rural community-based palliative care program.

Home-based care delivery helps meet the goal of keeping chronically ill individuals in their preferred setting, and has been shown to be the most cost-effective of palliative care models (McKinley, Shearer, & Weng, 2016). The lower cost of care delivery makes this a realistic option for resource-limited small rural organizations. One approach is to incorporate chronic care management into existing clinic-based PCMH models with RN care coordinators focusing on this patient panel. Another viable option is to incorporate the palliative care program into existing home care or hospice services. These agencies, which may be part of the health system or independently operated, are experts in providing in-home care, allowing the organization to leverage established staff, care protocols, and referral patterns. Hospice providers also have an

established skillset with caring for those nearing end of life and could easily be trained in palliative care techniques.

Multi-disciplinary care teams are also essential to a successful program. In a rural setting, the care team is most likely to be led by an RN. Other team members include PCP's, social workers, chaplains or other spiritual care providers, pharmacists, and other ancillary specialists. The center of the care team consists of patients and their families. Shared decision-making in the care planning process increases the likelihood that they will better understand the situation, comply with treatment, and meet established care goals. It also reduces the stress on caregivers by increasing the level of support and providing a forum to share concerns. Ongoing formal care coordination conferences are held with the team members to assess changes in patients' conditions and adjust plans of care to meet their needs. This approach should result in reduced utilization of acute care services and keep these patients comfortably in their home setting.

Connection to palliative care specialists is imperative to any rural community-based program. While the care coordination team, with appropriate training, should be able to manage the majority of patients, complex cases require consultation with palliative specialists. Most rural facilities will not have palliative specialists on site. However, they may be available as part of a larger health system or can be contracted through a shared services model with other rural partners. Consultations are provided for new complex patients as well as for those whose prognostication may result in complex secondary complications. Depending on geographic proximity to specialists, the consultations may be conducted in person or utilizing technology such as telehealth. Regardless of which model is employed, palliative care specialists serve an

important role in supporting a local program when needed, while the consultative nature of their role helps reduce overall costs of operation.

A shift in the delivery of end of life care will not be successful without extensive community outreach to facilitate discussions about death and dying. This is a topic most people would prefer to avoid. Nevertheless, current culture and perceptions cannot be altered without providing clear factual data to the general public so they can thoughtfully review their own beliefs on end of life treatment. Engaging the community through focus groups and skill-building workshops can help identify knowledge gaps. By removing the taboo from this issue and providing a venue for spurring discussion, individuals will be more likely to initiate honest and meaningful communication with loved ones and physicians and complete advance care planning documents (Wholihan & Pace, 2012). Evidence shows patients generally would prefer these conversations occur earlier in the care process and that community-based advance care planning demonstrated an improved correlation between the types of care outlined and care received (Wholihan & Pace, 2012). Continuing provider education is also necessary to change referral patterns to palliative care services and to help connect healthcare workers to the palliative plan of care approach. Organizations such as the End of Life Nursing Education Consortium (ELNEC) provide custom online curricula focused on core areas of palliative care and support evidence-based best practice in delivering care to this population.

Integrated ACP tools are a vital support to palliative care. Investing in a preferred ACP tool such as Respecting Choices or POLST will provide a standardized approach so caregivers can refer to documented directives for care, both in the home and in the event of hospitalization. Incorporating ACP into the EMR structure further strengthens the chances that all settings follow the directive. Organizations will need to allocate resources to establishing workflow to support

the access and review of ACP documents during clinical care. They also will need to develop training for personnel across the care continuum to ensure they are consistently and properly followed.

Discussion

Once an organization has determined that implementing a palliative care program is the right choice for their service area, it is imperative to involve community as well as internal stakeholders in the evaluation and implementation process. Collaboration with key partners will help garner support for the program, develop a customized model best suited to the unique attributes of the community, and increase the likelihood it can be sustained. The evaluation should include a synopsis of beliefs and assumptions as well as external factors affecting the program implementation. It is also important to establish metrics for measuring program success. Finally, a detailed plan should be created that includes specific activities to support defined short, mid, and long-term outcomes of the program.

Rural Evaluation and Implementation Plan

Organizations may find it helpful to conduct a formal evaluation process to develop a tailored implementation plan for their community. Identifying and engaging community stakeholders is a first step. Examples of program partners include public health, faith-based organizations, other community healthcare providers, and groups that serve elderly and disabled residents. The majority of rural hospital entities are organized as non-profits. The Internal Revenue Service (IRS) requires these organizations conduct a prescribed Community Health Needs Assessment (CHNA) every three years to maintain its tax-exempt status (IRS, 2011). The CHNA also requires a detailed implementation plan for the top identified local community needs and a measurement mechanism to monitor progress. By identifying palliative care as a key component of the CHNA, small rural facilities can utilize already dedicated resources to facilitate discussions with stakeholders and create an implementation and evaluation plan. Many community partners are accustomed to participating in the development and review of the

CHNA, so developing this program would be a natural extension of an established process and capitalizes on the healthcare organization's role as integrator for community health agendas.

One effective method to organize the assessment and implementation tactics for a new health program is a logic model. A logic model identifies the inputs, outputs, outcomes assumptions, and external factors for a specific program and helps to focus efforts on the activities most likely to positively influence desired results. Logic models are well-known within the healthcare industry and often used by public health agencies as well. A sample logic model for implementing a community-based palliative care program in a rural setting can be found in the Appendix. The logic model broadly outlines the major goals of the program, identifies specific implementation activities and measurement concepts, and defines preferred short, medium, and long term outcomes that would demonstrate successful program execution.

Executive and provider project sponsors should be identified to establish a dyad model to link administrative and clinical leadership for the program. Accountability for each defined activity should be assigned to members of the implementation team to assure completion of efforts according to the outlined plan. The logic model should be used as a guide to drive specific implementation tactics and help the team develop and adhere to a reasonable timeline. It should also include specific key milestones within the project timeline, and activities should be reviewed and refined throughout the implementation period.

Several implementation activities are necessary regardless of the specific model selected. For example, one short-term activity should include community outreach and education on palliative care and ACP services to improve awareness and gain support of local residents, which will eventually lead to an outcome of higher participation rates within the program. Establishing the palliative care provider care team, developing policies and procedures, and enhancing

education on clinical palliative care models is also important early in the implementation period. Mid-term activities include development of specific clinical decision support tools and workflows to bolster patient referrals to the program. Longer term activities include advocacy for enhanced reimbursement of palliative services and negotiation with commercial payors for population-based shared savings incentives.

Outcomes should also be broken down into short, mid, and long-term milestones. In the short-term, a key outcome would include attendance rates of education forums. Mid-term outcomes would include increased rates of completion of ACP, improved rates of patient referrals to palliative care, and reduction of transfers of patients out of the service area to seek palliative services in larger communities. Long-term outcomes address overall population health imperatives, including a reduction in acute-care utilization for palliative patients, improved adherence to ACP documents, and improved rates of matching place of death with patients' defined preference. Last, over time, the organization should be able to measure a reduction in healthcare costs per patient and seek to use this data to improve their reimbursement from payors.

Future Research

The solution outlined in this paper describes the crucial elements of a palliative care program that could be successfully deployed in a small rural community with limited resources. It focuses on the evaluation and implementation of such a program and offers a conceptual framework and logic model to concentrate efforts on those activities that will best support an effective application of palliative services in a rural setting. However, it does not address the financial shortfalls caused by current limited reimbursement of palliative care and ACP activities that make it difficult to sustain a robust program. Future research is needed to better understand

the inadequacies of funding for palliative care and ACP and to advocate for new government and commercial insurance reimbursement models to support further expansion of these services.

Conclusion

The United States' has a significantly higher outlay on healthcare delivery, but continues to see poorer health outcomes than other developed countries (WHO, 2016a). A small number of patients with complex chronic conditions account for a disproportionate share of this expenditure (Meier, 2011). Palliative care programs have been shown to be an integral component of the healthcare continuum and demonstrate improved quality of life and better adherence to care plans in alignment to individual patient beliefs and values, while also delivering reduced overall healthcare spending (Meier, 2011). Despite supporting Triple Aim objectives, programs have been out of reach for many small rural organizations with limited resources (McKinley, Shearer, & Weng, 2016).

Several innovative community-based models have emerged that incorporate proven evidence-based protocols that can be applied in home or outpatient settings. While rural communities have higher rates of health disparities than their urban counterparts and face numerous other barriers, they also have unique characteristics that effectively support the collaboration necessary to establish community-based programs. Successful palliative care programs share several core components: They are home-based and employ a multidisciplinary care coordination model centered around shared decision-making with the patient, connect teams led by RN's to palliative care specialists for complex cases, establish and support ongoing education for both providers and community members, and integrate ACP tools.

Rural communities considering integrating palliative care into their service continuum may benefit from using a formal evaluation framework, such as the sample logic model

presented, to identify and focus efforts on implementation activities most likely to produce desired results. Establishing palliative care in rural communities is an important step toward expanding access to services for some of the nation's most vulnerable residents and advancing the imperatives of the Triple Aim. However, future advocacy efforts are necessary to support the development of new reimbursement models to sustain palliative care programs and for chronically ill populations to fully realize their benefits.

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Appendix

Logic Model Example - Implementing a Rural Community-Based Palliative Care Program**Program:**

A community-based palliative care program in a small rural setting.

Evaluation Focus:

This a goal-based evaluation of the planning and implementation of a community-based palliative care program including strategies tailored to specific community needs and rural clinic resources. The evaluation will be based on an evidence-based set of practice strategies and recommendations. Program evaluation goals will be linked to established national and local palliative care protocols and best practice.

Situation Statement:

This community is committed to the Triple Aim goals of improving the health of our patient population, enhancing the patient experience, and reducing the per capita cost of care. Palliative care is one of the fastest growing specialties in the United States, but rural communities lag behind their urban counterparts in developing sustainable programs to serve the chronically ill nearing end of life. Rurality has been documented as a primary social determinant of health and rural residents suffer more health disparities. Implementing an evidence-based community palliative care program based on best practice guidelines for care has been proven to be clinically effective and is a highly cost-effective means to improving overall patient health and combats rural health disparities. This logic model will evaluate the components necessary to successfully implement a rural community-based palliative care program.

Inputs	Activities		Outcomes – Impact		
	Activities	Outputs	Short	Medium	Long
<p>Program budget</p> <p>Patient-centered medical home (PCMH) or home health agency care coordinator</p> <p>Multi-Disciplinary Clinical Care Team (Primary Care Provider, Social Worker, Pharmacist, Spiritual Care, Ancillary Providers, Palliative Care Specialist)</p> <p>Technology (EMR, electronic scripts and documentation process), Telemedicine access and support</p> <p>Organizational policies and procedures</p> <p>Advance Care Planning (ACP) Platform and Tools</p>	<p>-Implement a community-based palliative care program for chronically ill patients</p> <p>-Establish care teams that can add palliative care model to existing services (PCMH or home care agency)</p> <p>-Adopt a standard ACP tool (Example is POLST)</p>	<p>-Establish RN Coordinator to lead program development preferred setting (home or primary care clinic based)</p> <p>-Budget developed</p> <p>-Protocol developed and embedded within EMR</p> <p>-Staff trained on EMR ACP workflow and preferred patient referral process</p> <p>-Adopt system policies and procedures</p> <p>-Leadership and board support of resources needed to implement and maintain a palliative care program within the primary care or home health setting</p>	<p>-Establish or increase local access to palliative care program and resources</p> <p>-Program completed according to plan and timeline</p> <p>-Budget approved</p> <p>-Engagement of PCP team to change practice model/behaviors and adhere to prescribed workflow and interviewing techniques for patients meeting established criteria for referral to palliative care</p>	<p>-Increase referrals to palliative care program</p> <p>-Percentage improvement provider adherence to program referral protocol</p> <p>-Percentage improvement in clinical care team utilization</p> <p>-Keep more chronic care practice local and in the home setting</p>	<p>-Change in practice culture and practice patterns</p> <p>-Reduce rate preventable hospital admissions due to chronic disease</p> <p>-Demonstrate improved clinical quality and patient satisfaction in palliative care population through best practice metrics</p>

<p>Patient Educational materials</p> <p>Training in evidence-based protocols</p> <p>Staff outreach and education plan</p>	<p>-Develop standard patient education materials</p> <p>-Conduct initial and ongoing training in ACP and palliative care assessment protocols</p>	<p>-Number of patients meeting risk criteria screened according to decision support tool</p> <p>-Number of patients enrolling in palliative care program</p> <p>-Number of patients completing ACP activities and advance care directive</p> <p>-Number of patients whose care matches ACP</p>	<p>-Increase percentage of patients screened based on eligibility criteria</p> <p>-Increase awareness of palliative care services within community</p> <p>-Increase knowledge of healthcare workers on the role of palliative care, ACP, and end of life conversations</p>	<p>-Increase percentage of eligible patients enrolling in palliative care program and improve enrollment rates earlier in disease process</p> <p>-Increase patient support and satisfaction through palliative care model</p> <p>-Increase rate of ACP activities</p>	<p>-Integrate ACP and palliative care into healthcare continuum</p> <p>-Improve acceptance of palliative care as an evidence-based care pathway for chronically ill</p>
<p>Community palliative care and ACP campaign</p>	<p>-Identify/develop a community stakeholder group</p> <p>-Add palliative care to community health needs assessment objectives</p> <p>-Train community ACP facilitators</p>	<p>-Attendance of community-sponsored education events</p> <p>-Number of participants in community-based ACP activities</p>	<p>-Community stakeholder group agrees that palliative care access is an important need</p> <p>-Strengthen relationships with community partners</p>	<p>-increase cohesive collaboration, education, and ACP efforts</p>	<p>-Integrated community strategic plan to educate public on palliative care services and ACP tools (partner with public health, skilled nursing and assisted living facilities, faith organizations, and educational institutions)</p> <p>-Improve rate of ACP and palliative care utilization</p>

Beliefs and Assumptions:

- Most people, when educated about palliative care and advanced care planning, would prefer to be offered these services in a home setting and are likely to participate if meeting the criteria
- There is insufficient local access to palliative care services to meet current and increasing demand as the population ages
- Evidence-based studies support palliative care improves quality of care at end of life, reduces high-cost acute care utilization, and results in increased patient and family satisfaction
- Rural primary care provider shortage and turnover can dramatically impact program success

External Factors:

- Rural communities tend to have older, sicker, and poorer populations
- Limited funding exists for establishing and sustaining palliative care programs.
- Current reimbursement models do not adequately support these services
- Many community-based palliative care models exist and they are becoming more common in rural settings
- There is increased acceptance of palliative care services and advanced care planning as part of the natural aging and dying process