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Developing Successful Palliative Care Teams in Rural Communities: A Facilitated Process

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Abstract

Background: Developing palliative care (PC) programs in rural settings is challenging due to limitations on training, staff, resources, and reimbursement. Employing established frameworks and processes can assist rural communities in developing quality PC programs.

Objective: We sought to employ a facilitated community-centric planning process to guide several rural community teams across three states in the United States to support PC program development.

Materials and Methods: This is a prospective, observational, quality improvement initiative implemented over 18–24 months.

Results: A total of 17 community teams volunteered to participate in the process and completed initial assessments that identified gaps in clinical PC skills in several aspects of PC, including bereavement care, care continuity, pain and symptom management, and communication with family. Teams also identified barriers to optimizing PC for patient and families, including limited community awareness, poor reimbursement mechanisms, lack of resources and experience with PC, and inadequate care coordination. All 17 community teams developed and worked on implementation of a community-specific action plan to develop PC services. However, due to staff capacity limitations imposed by COVID-19, only eight communities completed a follow-up assessment in late 2020. These teams showed some improvement in knowledge of multiple PC domains as a result of the process and provided qualitative feedback indicating that the process was helpful in building capacity to offer needed services and developing the skills and workflows necessary to support delivery of PC.

Conclusion: This unique development process can help rural communities organize, develop, and sustain PC programs and overcome common barriers to providing PC.

Keywords: implementation science; palliative care; rural health

Introduction

RURAL POPULATIONS TEND to be older, have higher mortality, be more likely to suffer from a chronic condition or physical disability, and be of lower socioeconomic status than those in urban areas, but have less access to palliative care (PC) services and support than their urban counterparts. Providing PC in a rural setting is challenging. Many rural communities wanting to offer PC face barriers associated with a lack of clinical training, resources, or dedicated PC staff. In addition, rural communities often do not have access to hospice or PC specialists, and payment mechanisms are inadequate to support PC programs where patient volume is low. 9,10

Models and guidance for how best to provide PC in rural settings are limited. Most PC programs were originally developed in urban tertiary hospitals with interdisciplinary teams led by specialty-trained physicians. Urban areas are better able to support hospital- and community-based PC programs than rural areas, as patient volumes are large enough to allow a team to specialize in palliative medicine.

Provision of hospital-based PC services has been shown to reduce direct hospital costs such that there is an overall financial benefit for the facility. While there are examples and examinations of successful community-based PC programs 12-14 and previously established quality measures for these programs, 15 the published literature offers little guidance for those in rural areas. 16

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Community-based PC programs have been shown to lower costs and reduce hospital and care utilization. ^{17,18} They also extend the reach of services to nearly anywhere patients live and can be provided in clinics, homes, or nursing facilities. In rural areas, using a community-based model of PC allows health care providers to better meet the needs of patients across the continuum of care and, through collaboration with a variety of partners, can help align services to address medical and nonmedical needs to improve quality of life.

Community-based PC programs can also help identify patients with complex care needs earlier in their disease progression to address issues and challenges before they result in hospitalization. In addition, health care organizations are increasingly incentivized to measure quality and reduce costs, and community-based PC programs are one strategy to address the needs of patients who are potentially high resource users.

PC programs can support those serving as caregivers to loved ones as well. Caregivers who live in rural areas spend more time providing care and are more likely to care for multiple people than those in nonrural areas, ¹⁹ suggesting a greater need for caregiver support.

A successful community-based PC program typically leverages an interdisciplinary team to manage and coordinate patient needs, administrative tasks, and care delivery. ^{12–14} The core elements of PC can be met in rural communities through three critical processes: community capacity-based planning; coordination among health care settings and community services; and development of clinical skills through workforce training.

This article describes a community-centric facilitated planning process that uses a strength-based capacity approach to help guide teams through PC service development, while providing key resources and opportunities for peer learning to build necessary skills and workflows. The community-centric

approach is ideal for limited-resource rural environments since it focuses on connecting and leveraging existing community strengths. It involves teams of representatives from across the health care and community service continuum working to collaboratively identify and build on existing assets that can support targeted PC needs. We present the results from an initiative that guided multiple community teams in North Dakota (ND), Washington (WA), and Wisconsin (WI) through this process.

Materials and Methods

Conceptual framework

The design for this project was based on a model of community capacity development previously implemented by Stratis Health in 26 rural communities, primarily in Minnesota, as well as in North Carolina, Mississippi, and ND from 2008 to 2014. This community-centric framework assesses current needs and resources, focuses on alignment with national standards, and provides a facilitated structured planning process for development and implementation. The three interdependent elements of this program development approach are the foundational components, process development, and service implementation (Fig. 1).

- Foundational components include education and awareness of professionals and community members, the development of primary PC skills, and an established process for advance care planning and communication of those plans.
- Process development includes service workflow, connecting clinical professionals with community services and supports, and developing the business case for PC.
 Community teams are encouraged to use a quality improvement approach for implementation of PC services.

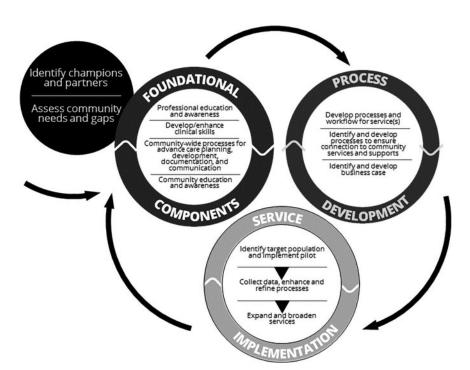


FIG. 1. Conceptual framework for rural community-based PC service development. PC, palliative care.

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As processes are established, this involves identifying a limited target population and using small tests of change to develop and refine workflows before expanding and broadening.

With service implementation, a key success factor is the interdisciplinary community team that is assembled and cultivated. Maturity of this team can be described as a progression from building, to evolving, to thriving.

Figure 2 describes how each of these stages look for the different roles and processes involved in a successful rural PC program. At the onset, there may be gaps in clinical knowledge or community awareness, a variety of processes employed, and inconsistent communication. By the time the team is thriving, however, processes and communication channels have been established and refined, skills and knowledge integrated across the team, care plans documented and accessible, and the wider community understands, supports, and requests PC services and resources.

Program description

In this initiative, the State Offices of Rural Health in each of the three targeted states served as lead organizations to support community-level implementation using the structure, process, and tools provided by Stratis Health (State Offices of Rural Health were compensated for their time and effort through grant funding). To help align state-level resources and support for the community teams, each state-lead organization established a state-level advisory group that included broad representation from a variety of stakeholders. This group provided input on an environmental scan of state-based opportunities and challenges related to implementation of rural communitybased PC, advised during the program implementation, and assisted in addressing infrastructure needs, such as workforce training, technology, and payment/regulation.

In addition to the training and resources, Stratis Health provided access to a curated rural-focused online resource center to help community teams connect to relevant resources to address common barriers such as clinical training and reimbursement or funding strategies.

As the lead organization in each state, the State Offices of Rural Health led recruitment and implementation support for community cohorts as outlined in the terms of the participation agreement detailed in Figure 3. In general, the lead organizations agreed to recruit five to eight community teams, support a facilitated planning process with each team, enable networking and communication among the participating community teams, and provide guidance and assistance during implementation. Similarly, participating community teams had to be willing to coordinate a multiorganization interdisciplinary planning group, take part in specific activities to learn about and develop services, and participate in sharing and collaboration with other teams.

Stratis Health provided the training, structure, tools, and process for the facilitated planning process, as well as overseeing oversight and coordination offing various components and educational offerings.

Recruitment and program participants

Targeted outreach to rural health care organizations through the State Offices of Rural Health and other partners in ND,

Rural Palliative Care: Community Team Development BUILDING **EVOLVING THRIVING**

Palliative Care Leadership

- Small group of inspired individuals
- · Assesses needs and gains support
- · Benefit of palliative care services is shared with atients, families, and providers
- · Understands and supports palliative care development
- · Provides motivation and resources
- for further palliative care develop Empowers staff to build strong processes and consistent services

Advance Care Planning Processes

- A variety of processes and formats iders and settings Sharing across settings is limited
- Alignment of processes and formats among roviders and settings
- · Plan in place for sharing across settings of care
- · Aligned process, format, and communication
- channels across settings and the community · Patient wishes are documented, accessible and followed

Clinical Team - Palliative Care Skills, Interdisciplinary Team

- e care skills are limited tside of hospice providers rdisciplinary team (IDT) ussions are inconsistent
- Increased awareness and palliative care skill building across broader sections of the health care workforce
- IDT discussions are more regular and structured
- Skills and knowledge are fully integrated across the team
- · Formal and regular IDT meetings · Linkages are strong for additional expertise and support as needed

Care Coordination, Collaboration with Community Services and Supports

- Limited; may be highly
 Limited; may be highly of resources and/or patient
- · Services and access points are understood
- Identification of needs and gaps completed at a community level; care plans shared intermittently
- Referral and service processes are integrated across settings
- · Care plans accessible, utilized, and dynamic; service development expands for identified gaps

Community Awareness of Palliative Care

- Limited and may be highly patients, and families
- · Common language about palliative care utilized among community partners
- · Palliative care services are visible and becoming
- Community understands, supports, and requests palliative care services and resources

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Lead Organizations Agreed to:

- Provide qualified staff with expertise in PC and clinical quality improvement
- Develop and facilitate opportunities for participating organizations to come together for a collaborative education and visioning session for learning, planning, and networking
- Provide technical assistance to each community as it developed an action plan for PC services
- Designate a primary liaison to serve as the lead contact person for each participating community to have ready access to program resources
- Maintain a strong commitment to leverage opportunities to advance the project through partners and stakeholders, and to promote the accomplishments and learnings of participant communities
- Conduct asset and gap analysis with each community team at the beginning of the project and an evaluation at the end
- Provide opportunities for networking with other communit teams and access to educational resources to assist communities in planning and implementation
- Provide ongoing updates to participating communities as new rural PC resources and tools became available

Participating Organizations Agreed to:

- Form a multi-site, interdisciplinary team representing more than one provider setting committed to PC services develoment
- Participate in two in-person education and visioning sessions, technical assistance conference calls, and any additional recorded or live web/teleconference sessions offered during the initiative
- Develop an action plan for developing and/or enhancing PC services in their community
- Designate a community team leader to drive the community's PC efforts, serve as the main contact for the lead organization, and serve as an external spoksperson as needed. Teams also needed a physician champion to support the work and engage medical staff
- Share experiences and strategies for PC implementation with other community teams
- Complete an asset and gap analysis related to PC services implementation at the beginning of the project and an evaluation at the end
- Agree to be recognized publicly as a participant in the project
- Collect and submit data as requested
- Remain active in the project throughout the duration of the initiative

FIG. 3. Lead and participating organization terms.

WA, and WI was performed to recruit rural community teams. Community teams that expressed interest were asked to sign a participation agreement that outlined the support they would receive and the need to assemble the necessary staff and resources. Timelines were staggered across the three states, with most teams launching work in mid-2018 and ending in late 2020.

The program included assessments of current PC-related services and expertise; facilitated planning workshops; conference calls with other participating communities; technical assistance calls; educational sessions; ongoing consultations with Stratis Health and the State Office Rural Health; and links to resources.

Data collection and analysis

Community teams completed an initial assessment that served as a community asset and gap analysis. This assessment covered several areas, including available components of PC services; level of expertise or certification in PC among team members; information on care settings and patient populations; educational needs or opportunities; support systems in place (e.g., case management, respite care, and transportation); quality mechanisms and measures; and perceived barriers. Examples of questions included the following:

- "Rate your overall health care community's current level of experience/expertise in... pain management, bereavement, etc."
- "Rate how well you believe current care transition processes meet the needs of patients in your community"
- "Which staff have training/certification in palliative care?"
- "Rate the following barriers to providing PC that may affect your community"

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A follow-up assessment at the end of the program was used to collect information regarding changes to the community programs, key learnings, and barriers. Team responses were summarized and aggregated. For the subset of communities with both initial and follow-up assessments, descriptive comparisons were made, but statistical significance was not examined due to the small sample size. The NORC Institutional Review Board approved all aspects of primary data collection.

Results

Seventeen communities of varying size and rural status across ND, WA, and WI were represented in the initial assessment. Most have rural-urban commuting area codes of 7 ("small town core") or 10 ("rural area"), although some have a code of 4 ("micropolitan area core"). Eight are designated as frontier communities, which is defined as "sparsely populated rural areas which are isolated from population centers and services."²¹

Makeup of the community teams themselves also varied; some were associated with larger health systems, while others were not; some were associated with a single town and surrounding area, while others covered multicounty areas. Results of the initial assessment for the 17 participating community teams are shown in Table 1.

The most common PC service components available at the time of initial assessment were spiritual care (100%); home care (94%); home health services (94%); transportation (94%); hospice care (82%); and access to a social worker (82%). Least common were bereavement care (35%); pain management (35%); and parish nursing (24%). Four communities had at least one PC or hospice board-certified nurse practitioner or physician.

Community responses regarding the level of training, education, and expertise demonstrated notable deficits. When asked to rate their community's current level of expertise or experience (on a scale from 0 [lowest] to 4 [highest]) in eight different components of PC, the majority self-rated themselves as a 2 or lower in seven of eight areas. The percent of communities giving themselves a "high" self-rating of 3 or 4 in these areas ranged from only 6% to 29%, except for hospice services, where 76% self-rated as 3 or 4. When asked how well pain and symptom management were being met, 0% self-rated their community a 4 and only 18% self-rated

their community a 3. A similar result was found for how well they self-rated their ability to meet care transition process needs (0% self-rated as a 4 and 24% as a 3).

Barriers identified as the most impactful (reflecting the highest percentage of communities rating them as a 3 or 4) were community awareness (76%) and reimbursement (76%); human resources to provide services (59%); lack of clinician knowledge/experience with PC (53%); coordination of care between providers/settings (41%); and medical staff commitment/buy-in to PC (29%).

Because the later timeframe of this project coincided with significant activity related to the pandemic, only eight community teams were able to complete follow-up assessments, even though all teams had developed and launched implementation on a community-level action plan for PC development. Results of the initial assessment in this subgroup were similar to those of the entire group of 17 (Table 1).

Among the eight communities with both initial and followup assessments, some improvement was seen in self-ratings (Table 2). For example, within questions related to expertise or experience, improvements were seen in all eight PC service components, except for access to hospice (which was already rated highly at initiation). The largest improvement was seen in interdisciplinary team care. The areas most frequently showing improvement included staff education (seven teams); interdisciplinary team care (six teams); bereavement care; and pain and symptom management (five teams each).

A (blinded) case example is shown in Figure 4. This community had an independent critical access hospital and an integrated health system, but home health and hospice services were not available locally. Over 18 months, they improved staff education, extended outreach, procured a hospice contract, and recruited a physician with PC experience. At the end of the program, they were in the process of launching a palliative consult process across multiple care settings.

Several communities provided positive feedback through qualitative comments. One community said, "This was a good opportunity for us to bring people from our community together, as we had hospital and clinic staff, clergy, nurses, doctors, and community members get to know each other. The ability to make our services known, and combining our resources for the betterment of patients who need palliative

Table 1. Initial Assessment Reponses: Self-Reported Rating^a on Their Community's Current Level of Experience or Expertise in Specific Palliative Care Service Components

	Full group (n = 17) Self-rating			Subgroup with follow-up (n = 8) Self-rating		
PC service component	0–1	2	3–4	0–1	2	3–4
Bereavement care (apart from hospice)	53%	29%	18%	63%	13%	25%
Continuity of care/care management	18%	53%	29%	0%	63%	38%
Family conferencing with goals of care discussions	24%	47%	29%	13%	50%	38%
Access to Hospice	24%	0%	76%	13%	0%	88%
Interdisciplinary team care	29%	47%	24%	38%	50%	13%
Staff education on palliative care	65%	29%	6%	75%	25%	0%
Pain and symptom management	29%	53%	18%	25%	50%	25%
Care transition processes	18%	59%	24%	13%	63%	25%

^aSelf-ratings go from 0 (lowest) to 4 (highest).

PC, palliative care.

Care transition processes

38%

Percent with low self-rating Percent with high self-rating $(0 \ or \ 1)$ (3 or 4)Initial assessment Initial assessment Follow-up Follow-up Bereavement care (apart from hospice) 63% 0% 25% 38% Continuity of care/care management 0% 0% 38% 63% Family conferencing with goals of care discussions 13% 0% 38% 50% Hospice 13% 13% 88% 88% Interdisciplinary team care 38% 0% 75% 13% Staff education on palliative care 75% 0% 13% 25% Pain and symptom management 25% 0% 25% 63%

13%

Table 2. Changes from Initial to Follow-Up Assessment for Subgroup with Both (n=8)

care, enables us to reach as many people as possible." Others lauded the opportunity for continued development, while recognizing some of the persistent barriers: "Our health system and community team love this program and hope to continue to have the services grow, but it would be great if we could get paid for all our hard work."

Regarding the framework and structure guided by Stratis Health, one state partner appreciated that the technical assistance and flexible guidance provided by the program allowed them to "forge their own path" in supporting the development of services in participating communities. Sev-

eral partners noted the dedication and passion common among individuals drawn to working in and on PC and enjoyed the opportunity to connect and network with likeminded individuals.

25%

Discussion

Rural community teams that participated in this program reported significant deficiencies at program initiation in experience/expertise as well as processes for care transitions and pain/symptom management. Common barriers cited

Community: Located in a Frontier area, primarily agriculture based but with rapid population growth due to energy boom (population increase from approximately 2000 to more than 10000 in three years). More than 50 miles to nearest hospital.

Health Care Infrastructure: Independent CAH and integrated health system (hospital, clinic, nursing home) that participates in a Medicare ACO and serves a county geographically larger than Delaware. Home health and hospice services not available locally

0%

Community team leader: RN who is also the diabetes educator for the health system.

Community team representatives: Hospital DON, Long-Term Care DON and social service designee, Family Nurse Practitioner, Chronic Care Manager, Cardiac/Pulmonary Therapy, Clinic manager, local clergy, senior companion program, social services, EMS, local pharmacy, Extension Services representative

Initial Action Plan Focus Areas:

- · Formalizing team structure and identifying roles
- Development of a community-wide resource list
- Improvements in advance care planning including facilitator training and workflow/documentation in EMR
- Staff and clinician education

Over the next 18 months:

- Significant progress on staff and clinician education (recognized as a CAPC Tipping Point Challenge winner)
- Broad outreach to improve acceptance of ACP in the community, incorporation of ACP in annual wellness visit process, focus on POLST order completions for appropriate patients,
- Procurement of hospice contract for respite and inpatient admissions
- A physician with palliative care experience was recruited to the community and joined the team
- In process of launching palliative consult process across inpatient, clinic, and LTC prior to COVID. Had to pause roll-out and expansion while staff attention shifted to address COVID related priorities.
- Anticipate community team planning and next steps will re-launch later in 2021.

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include a lack of PC experience/expertise in their community as well as reimbursement mechanisms. Those with follow-up assessments demonstrated improvements in multiple areas and provided qualitative evidence of program benefits.

Qualitative feedback from the communities revealed several things. In general, those who participated felt they were able to build the capacity to offer the needed services and the facilitated planning process allowed them to build the skills and workflows needed to support PC offerings. There was variety across community teams in access to and participation across different disciplines, but this did not negatively affect the ability of the program to facilitate development of PC services.

The qualitative feedback made it clear that there are key components of the process that promote success of PC program development. These were as follows:

- Identifying local leadership to champion PC
- Providing access to training, education, resources, and peer networking
- Having a facilitated planning process to guide local action planning and implementation
- Promoting flexibility in interdisciplinary team composition to be responsive to specific community needs and assets

The need for PC in rural areas is increasing, including for specific conditions like cancer²² and dementia.²³ Rural communities face unique challenges; those providing care are typically required to serve in several roles²⁴ and travel long distances.^{24,25} Given that many community members lack awareness or understanding of what PC entails,²⁶ those providing care must also serve as educators in the community. Thus, the need is great for a structured framework and process for developing and providing PC programs in rural areas. We are encouraged by the results presented in this study and believe that following this process can help other rural communities develop access to high-quality and efficient PC.

Strengths of this initiative include the use of real-world settings and the inclusion of communities from multiple U.S. geographic regions. In addition, we obtained longitudinal observations to collect information on change and improvement for some communities. However, because the later part of this effort was implemented during the pandemic, community teams had limited time and resources to devote to the process, and only a small number were able to complete follow-up assessments.

Conclusions

Even with limitations, results demonstrate that a structured facilitated planning process can help rural communities develop and implement PC services, despite barriers. Additional resources and support are needed to continue to expand access to high-quality PC services in rural communities, including the continued need for flexibility in reimbursement structures that support an interdisciplinary community-based approach. Implementation and uptake of value-based care arrangements vary widely across rural areas.

Rural participation in value-based care programs from multiple payers has the potential to align payment incentives that support implementation of PC services. Additional opportunities include potential for better utilization of telehealth to access specialty-level skills and to provide in-home monitoring and support. Recent telehealth reimbursement and policy changes stemming from the pandemic should help enable use of technology to support service development.

Authors' Contributions

All authors confirm that they meet the criteria for authorship and that they have approved the final version of this article.

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Author Disclosure Statement

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