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Advancing Palliative Care Initiatives in Rural Communities: A Community-Centric Approach

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Abstract

Creating palliative care (PC) initiatives in rural areas presents difficulties attributed to constraints in training, workforce, materials, and financial compensation. The utilization of well-established structures and methods can aid rural regions in crafting high-standard PC programs. Our aim was to implement a guided, community-centered planning procedure, facilitating multiple rural community groups across three US states, to foster the advancement of PC programs.

Keywords: Palliative care; Rural communities; Community-centered planning; Program development; Interdisciplinary teams; Healthcare disparities; Qualitative feedback;, Value-based care; Tele-health integration

Introduction

Rural populations typically exhibit characteristics such as being older, experiencing higher mortality rates, having an increased likelihood of dealing with chronic ailments or physical disabilities, and often belonging to lower socioeconomic strata4 compared to their urban counterparts [1-3]. Despite these factors, rural communities face greater challenges in accessing palliative care (PC) services and assistance5 in comparison to urban areas. The provision of PC within a rural context presents complexities. Numerous rural areas aspiring to offer PC services encounter obstacles linked to insufficient clinical training, limited resources, and a shortage of dedicated PC personnel. Moreover, rural communities frequently lack access to specialized hospice or PC experts, and the payment structures are insufficient to sustain PC programs in regions with low patient numbers. Currently, there is a shortage of models and guidance outlining the most effective ways to deliver PC in rural settings. Urban locales possess better capabilities to sustain both hospital-based and community-oriented PC programs, primarily due to the larger patient volumes that enable the formation of specialized palliative medicine teams [4]. Evidence suggests that implementing palliative care (PC) services within hospital settings leads to a reduction in direct hospital expenses, ultimately resulting in an overall financial advantage for the institution. While there exist instances and evaluations of successful PC programs situated in communities, and established benchmarks for the quality of such programs, the available literature provides minimal guidance specifically tailored to rural contexts. Community-based PC initiatives have demonstrated their ability to lower expenses and curtail hospital and care utilization. These programs also broaden the scope of services to encompass almost any location where patients reside, spanning clinics, residences, and nursing facilities [5]. In rural regions, adopting a community-based approach to PC empowers healthcare providers to more effectively address the diverse needs of patients along the entire care spectrum. By collaborating with an array of partners, this model can align services to cater to both medical and nonmedical requirements, thereby enhancing overall quality of life.

Community-centered palliative care (PC) initiatives also play a pivotal role in early identification of patients with intricate care requirements, addressing issues and hurdles prior to escalation into hospitalization. Furthermore, the push for healthcare organizations to gauge quality and curtail expenses has intensified, making community-based PC programs a strategic avenue for tending to patients who might have high resource utilization potential. Inclusive of caregivers, PC programs can extend their support to those tending to their loved ones [6,7]. Caregivers residing in rural locales dedicate more time to caregiving and often oversee multiple individuals, setting them apart from their nonrural counterparts. This trend underlines an amplified necessity for caregiver assistance. Effectively established community-based PC programs commonly rely on interdisciplinary teams to oversee and synchronize patient needs, administrative responsibilities, and care provision [8,9]. In rural communities, the fundamental aspects of PC can be addressed through three pivotal procedures: planning anchored in community capacity, harmonizing healthcare settings and community services, and enhancing clinical proficiency through workforce training. This article delineates a facilitated planning process that is centered around the community, employing a capacity-based approach that emphasizes strengths. This process aids teams in navigating the development of palliative care (PC) services, accompanied by essential resources and opportunities for peer learning, facilitating the acquisition of necessary skills and workflows. Particularly well-suited for resource-constrained rural settings, the community-centric approach concentrates on harnessing and capitalizing on existing strengths within the community. It entails assembling teams comprised of representatives from various points along the healthcare and community service spectrum, collaboratively pinpointing and amplifying existing assets that can cater to specific PC requirements. The outcomes of an initiative that steered multiple community teams in North Dakota (ND), Washington (WA), and Wisconsin (WI) through this method are presented.

Materials and methods

The project's blueprint drew inspiration from a community

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capacity development model previously executed by Stratis Health across 26 rural communities, with a primary focus on Minnesota. This model was also implemented in North Carolina, Mississippi, and ND from 2008 to 2014. Framed around the community-centric ethos, this framework evaluates existing requisites and assets, aligns with national benchmarks, and orchestrates a guided, structured planning process to facilitate both development and execution. The program development strategy comprises three interconnected components: foundational elements, process advancement, and service implementation. The foundational aspects encompass educating and raising awareness among professionals and community members, honing fundamental palliative care (PC) skills, and instituting a mechanism for advance care planning and communicating these plans. Process advancement entails crafting service workflows, establishing links between clinical practitioners and community services, and formulating the rationale for PC from a business perspective. The community teams are encouraged to apply a quality improvement methodology for the implementation of PC services. As processes take shape, this involves pinpointing a specific target population and employing incremental tests of change to construct and refine workflows before embarking on expansion and enlargement. During the service implementation phase, the makeup and nurturing of an interdisciplinary community team stand out as pivotal success factors. The evolution of this team can be tracked through stages: from an initial building phase, progressing to an evolving state, and ultimately reaching a thriving level of maturity.

Program overview: Within this endeavor, the State Offices of Rural Health in the designated trio of states took on the mantle of lead organizations, spearheading community-level implementation with the aid of the structural framework, procedural guidelines, and tools offered by Stratis Health (compensation was extended to State Offices of Rural Health through grant funds for their dedication of time and effort) [10]. To streamline state-level resources and bolster support for community teams, each state-leading entity instituted a state-level advisory consortium, comprising a diverse representation of stakeholders. This consortium contributed insights to an environmental scan of state-specific opportunities and challenges associated with the integration of rural community-based palliative care (PC). They provided counsel throughout the program's execution and played a role in addressing foundational requirements such as workforce training, technological provisions, and regulatory considerations. Supplementing the training and resources, Stratis Health furnished access to a meticulously curated online resource hub, tailored to rural settings, enabling community teams to link up with pertinent resources to tackle common obstacles such as clinical training and devising reimbursement or funding strategies. As the primary organization in each state, the State Offices of Rural Health took the helm in recruiting and extending implementation support to community cohorts, in accordance with the stipulations delineated in the participation agreement depicted in Figure 3. Broadly, these lead organizations committed to enlisting five to eight community teams, guiding each through a facilitated planning process, fostering inter-team networking and communication, and providing mentorship and aid during the implementation phase [11]. Similarly, the participating community teams embraced their responsibility to orchestrate a multi-organizational interdisciplinary planning collective, partake in specific educational activities to cultivate services, and actively engage in the sharing of insights and collaborative efforts with fellow teams.

Recruitment and participants: To enlist rural community teams, a focused outreach effort was orchestrated in ND, WA, and WI, in collaboration with the State Offices of Rural Health and additional partners. Organizations within rural healthcare were the prime targets. Those community teams exhibiting interest were invited to endorse a participation agreement that elucidated the backing they would receive and emphasized the requisite assembly of essential personnel and resources. The timelines were coordinated across the three states, with the majority of teams commencing their endeavors in mid-2018 and concluding by late 2020. The program encompassed assessments of existing palliative care-related services and proficiency, workshops steered by facilitators, teleconferences uniting participating communities, technical support calls, educational sessions, continual consultations involving Stratis Health and the State Office Rural Health, as well as access to a wealth of resources [12].

Data collection and analysis: Community teams embarked on an initial assessment, functioning as an evaluation of community assets and gaps. This comprehensive assessment encompassed various dimensions, such as available components within palliative care (PC) services, the level of expertise or certification in PC possessed by team members, insights about care settings and patient demographics, educational requisites or opportunities, established support mechanisms (e.g., case management, respite care, and transportation), quality metrics and evaluation approaches, as well as perceived obstacles. Illustrative questions included: Evaluate your healthcare community's current expertise level in areas like pain management, bereavement, etc. Assess the adequacy of current care transition processes in meeting patient needs within your community. Which team members have received palliative care training/certification? Rank the hindrances to providing PC that might impact your community. Upon the program's culmination, a subsequent assessment was conducted to collect information regarding changes observed in community programs, noteworthy insights gained, and persisting barriers. The responses from the teams were synthesized and aggregated [13]. In cases where both initial and follow-up assessments were available for a subset of communities, descriptive comparisons were undertaken, although statistical significance was not pursued due to the constrained sample size. The NORC Institutional Review Board sanctioned all aspects of the primary data collection process.

Results

The initial assessment drew participation from seventeen diverse communities spanning ND, WA, and WI, encompassing a range of sizes and rural designations. A majority of these communities held rural-urban commuting area codes of 7 ("small town core") or 10 ("rural area"), though several were coded as 4 ("micropolitan area core"). Among them, eight were classified as frontier communities, characterized by their sparse population, remote nature, and detachment from central services. The composition of the community teams exhibited considerable diversity as well. While some were linked with expansive health systems, others functioned independently; certain teams were aligned with a solitary town and its adjacent locality, while others operated across multi-county domains. The barriers deemed most influential, as indicated by the highest percentage of communities rating them as a 3 or 4, encompassed community awareness (76%) and reimbursement challenges (76%). Other significant barriers included scarcities in human resources for service provision (59%); clinician knowledge and familiarity with palliative care (53%); effective coordination of care across providers and settings (41%); and securing medical staff commitment and buy-in for palliative care (29%). Numerous communities shared positive sentiments through qualitative remarks. One community expressed, “this initiative allowed us to bring diverse individuals from our community together hospital

and clinic staff, clergy, nurses, doctors, and community members fostering mutual understanding. The platform to showcase our services, coupled with pooling our resources to enhance palliative care for patients, empowers us to extend our reach far and wide." Others commended the prospect of ongoing growth while acknowledging prevailing hurdles: "Our health system and community team embrace this program, aspiring for its expansion. However, it would be highly beneficial if our diligent efforts were financially recognized. In relation to the framework and structure supervised by Stratis Health, a state partner highlighted their appreciation for the program's adaptable guidance and technical support, enabling them to carve a distinct path towards nurturing service development in the involved communities. Several partners underscored the shared dedication and fervor observed among individuals engaged in palliative care, relishing the chance to connect and form networks with like-minded peers.

Discussion

The rural community teams engaged in this program unveiled noteworthy insufficiencies upon program initiation, particularly in terms of expertise/experience and the efficiency of care transition and pain/symptom management processes. Commonly cited hurdles encompassed a dearth of palliative care expertise within their communities and hurdles associated with reimbursement mechanisms. Among those with follow-up assessments, discernible enhancements emerged across multiple domains, corroborated by qualitative testimony illustrating the program's advantages. Communities that participated generally voiced the conviction that they succeeded in bolstering their capacity to furnish essential services. The facilitated planning process proved instrumental in honing the skills and workflows indispensable for backing palliative care offerings [14,15]. While the extent of access to and participation across various disciplines exhibited variation among community teams, this diversity did not impede the program's capacity to catalyze the progression of palliative care services. The qualitative feedback underscores pivotal components within the process that foster the success of palliative care (PC) program development. These components encompass:

- Identifying local leaders to champion PC.
- Offering accessibility to training, education, resources, and peer networking.
- Incorporating a facilitated planning process that steers local action planning and implementation.
- Encouraging adaptability in the composition of interdisciplinary teams to address specific community strengths and needs.

The demand for palliative care in rural regions is on the rise, encompassing specific conditions like cancer and dementia. Rural communities grapple with distinct challenges; caregivers are often compelled to juggle multiple roles while traversing considerable distances. Given the prevalent lack of awareness or understanding regarding palliative care among community members, caregivers must also take on the role of educators within their community. Consequently, there is a pronounced need for a structured framework and process to foster the development and provision of PC programs in rural settings. The outcomes detailed in this study offer encouragement, suggesting that adhering to this process could empower other rural communities to establish access to high-caliber and efficient PC. Strengths intrinsic to this initiative encompass its reliance on real-world contexts and the incorporation of communities spanning diverse US geographic regions. Additionally, we garnered longitudinal observations to capture insights into the evolution and enhancement within select communities. However, it's important to note that due to the pandemic's impact on the latter phase of this endeavor, community teams faced constraints in terms of time and resources dedicated to the process. Consequently, only a limited number were able to complete follow-up assessments.

Conclusion

Despite its limitations, the outcomes underscore the efficacy of a structured and facilitated planning process in aiding rural communities to forge ahead with the development and execution of palliative care (PC) services, even in the face of challenges. To further extend access to top-tier PC services in rural settings, it remains imperative to infuse additional resources and support. This involves an ongoing requirement for flexibility within reimbursement frameworks, which can sustain an interdisciplinary, community-oriented strategy. It's noteworthy that the implementation and adoption of value-based care arrangements exhibit notable variability across rural regions. Engaging rural communities in value-based care initiatives spanning various payers holds the potential to harmonize payment incentives that bolster the integration of PC services. Further prospects emerge, including the potential to leverage telehealth for enhanced access to specialized expertise and for offering in-home monitoring and support. Recent policy changes and reimbursement adaptations in telehealth, influenced by the pandemic, are poised to facilitate the utilization of technology to bolster service development.

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Not applicable.

Conflict of Interest

Author declares no conflict of interest.

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