Improving Knowledge of Palliative Care in Rural South Dakota Through Community Education

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Purpose: To explore the effectiveness of education on increasing knowledge of palliative care and how to access palliative care services among community members.

Design: A descriptive study using a retrospective survey was conducted after in-person educational events on palliative care. This study used the definition of rural and frontier provided by the South Dakota Department of Health which is based on the US Census Bureau population estimates (2020).

Sample: Educational events occurred in 17 communities across South Dakota with 256 community members. Of which, 166 people completed the survey.

Methods: Wilcoxon signed rank test was performed to evaluate for change in palliative care knowledge. Fisher's Exact Test was utilized to analyze for an association between past palliative and hospice care use, palliative care knowledge, and confidence in finding palliative care services.

Findings: The majority of educational events took place in rural or frontier locations with 85% of participants and 95.2% of survey respondents attending in a rural or frontier location. Most of the survey respondents (61.5%) were a caregiver of someone with a serious health condition, while 13.3% had a serious health condition and 3% were both a caregiver and had a serious health condition. After completion of the community education program, community members demonstrated a statistically significant improvement in their knowledge of palliative care and their confidence in being able to locate palliative care services, $p < .001$. Having used palliative care services was significantly associated with palliative care knowledge and confidence in accessing these services, $p < .001$.

Conclusion: Performing education individualized to each community increased knowledge regarding palliative care and how to access these services. Additional needs of community members were discovered which is critically important to address as the rural population ages and is more likely to be living with serious illness(es).

Keywords: palliative care, community education, rural

Improving Knowledge of Palliative Care in Rural South Dakota Through Community Education

In the 2017 Call to Action, the American Nurses Association (ANA) and the Hospice & Palliative Nurses Association (HPNA) stated quality palliative care should be received by all patients, families, and communities experiencing serious illness (ANA, 2017). In previous research performed in South Dakota, a "poor conceptual understanding and awareness" of palliative care

was found among healthcare professionals, patients, families, and caregivers (Hawkins-Taylor et al., 2020, p. 561). In response to these findings, and others, the South Dakota Palliative Care Network (SDPCN) prioritized education as its next strategic initiative. The SDPCN is composed of palliative care champions across the state with a goal to improve awareness and knowledge of palliative care in communities along with future and current healthcare professionals throughout the region (Mollman et al., 2022).

To guide this work, the SDPCN desired a definition of palliative care that local palliative care experts agreed upon to allow for consistent messaging of what palliative care is. In collaboration with specialty palliative care providers and researchers in the state, a working definition of palliative care was developed with the local culture in mind. It was adapted from the definition by the Center to Advance Palliative Care (CAPC, n.d.). The South Dakota definition of palliative care states:

> Palliative care is medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of illness with the goal to improve quality of life for both the patient and family. Effective palliative care is delivered by a trained team of doctors, nurses, social workers, chaplains, and other health professionals who collaborate to provide an extra layer of support. Based on the needs of the patient, not on prognosis, palliative care is appropriate at any age and any stage of serious illness and may be provided alongside curative treatments in primary and specialty settings (adapted from CAPC, n.d., para. 2-3).

Recognizing the rural nature of the state, and the potential for limited local palliative care resources, the focus was on improving knowledge of primary palliative care. Unlike specialty

palliative care, primary palliative care can be delivered by any healthcare provider caring for patients requiring these services (National Consensus Project for Quality Palliative Care, 2018).
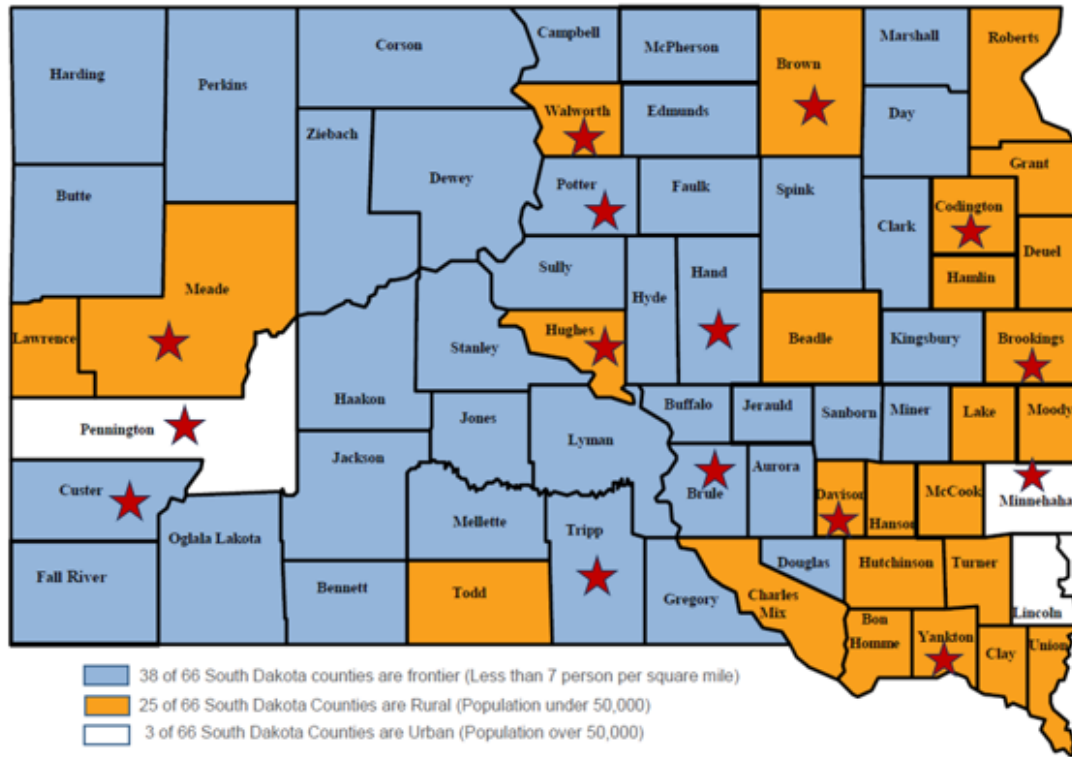
Rural Context

For the purposes of this work, the United States (US) Census Bureau classification of rural was used. The US Census Bureau considers rural areas to be geographic areas that do not have an urban classification (U.S. Census Bureau, n.d.). The community education team used a resource provided by the South Dakota Department of Health which is based on the US Census Bureau 2020 population estimates to identify rural and frontier locations in the state. This resource defines rural as a "population under 50,000" and frontier as "less than 7 people per square mile". According to this resource, only three of South Dakota's 66 counties are considered urban whereas 25 are designated as rural and 38 as frontier, see Figure 1. Fifty-two percent of South Dakota residents live in these rural and frontier areas (Rural Health Information Hub, n.d.). Consequently, providing education on palliative care in rural areas of the state became the focus.

Creating the Community Education

The aims of the community palliative care education were to: increase awareness of palliative care, differentiate palliative care from hospice, and discuss where to find services to support those living with serious illness. To meet these aims, the community education team planned to hold events at a minimum of 16 locations. Considering the rurality of the state, intentional focus was placed on rural and frontier locations in South Dakota for community education (Figure 1). While the majority of the community education events were held in rural or frontier counties, three events were held in urban areas as they have access to primary and specialty palliative care services.

Figure 1

Locations of Community Education Events

Note. The counties are designated as urban, rural, or frontier based on the United States Census Bureau, 2020 Population Estimates and was created by the South Dakota Department of Health Office of Rural Health. The Office of Rural Health shared this map with the South Dakota Palliative Care Network in 2021. The Network used this map to identify key counties for community education.

The community education team consisted of community healthcare professionals, educators, and SDPCN members. This team assisted in identifying and contacting organizations in the rural communities with a focus on senior programs and service organizations with established meetings. The team desired to hold the education during established meetings to facilitate attendance and reduce marketing needs. In addition, the team chose to hold the events in-person, rather than virtual, due to: 1) unreliable internet access in rural and frontier areas, 2) event locations were in

the community, often without technology and internet access, 3) ease of distributing the survey after the education, and 4) anticipation of an age group that prefers in-person events and may lack access to immediate technology (mobile devices). In South Dakota, it is estimated that one in six residents lack adequate access to broadband internet, making virtual education challenging (Center for Rural Affairs, 2022). The in-person format also allows for accessible and timely communication on the topics discussed (Zhang et al., 2022).

As a result of the COVID-19 pandemic, there was a delay in starting the education due to safety concerns and clinical requirements of the healthcare professionals related to surges. To address this delay, the team created an educational proposal outlining a plan for the community education to be completed over a 9-month period. An evidence-based community education template was used as a framework with permission from Stratis Health (n.d.). The presentation template was modified to match the palliative care resources available in each community. In the urban settings, specialty palliative care was presented including how to access these services. Whereas in the rural and frontier communities, primary palliative care was presented.

The community education was conducted by four healthcare professionals with a background in palliative care. When possible, a healthcare professional from the community was also present, which increased their awareness of palliative care and offered participants answers based on their local knowledge. The community education team felt it was important to engage with local healthcare professionals to raise awareness in case questions or discussions arose during future patient visits. The local healthcare professionals varied by discipline and setting depending on the community. The SDPCN had already created and marketed free, online continuing education on palliative care to healthcare professionals in these communities (Berke et al., 2023). Hence, resources were available if healthcare professionals were not able to attend the community

education event and/or they wanted to learn more about how to offer primary palliative care in their local practice.

Methods

The purpose of this study was to evaluate the effectiveness of community education on self-reported palliative care knowledge and confidence in finding palliative care services by community members. This descriptive study was approved by the Avera Institutional Review Board. Having the same four healthcare professionals performing the community education events facilitated standardized data collection for both the surveys and common themes of participant questions.

Data Collection

At the end of the 17 community education events, a demographic and retrospective survey was administered to community members who volunteered to participate and were over the age of 18. The demographic questions included race/ethnicity, gender, age, marital status, experience with a serious health condition, use of palliative care services, and use of hospice care services. The retrospective portion of the survey had four questions to assess self-reported knowledge of palliative care and one question to assess self-reported confidence in finding palliative care services. The team chose to administer the survey on paper due to the same reasons as choosing to hold the events in-person.

A retrospective survey is a common method of assessing "learners' self-reported changes in knowledge, awareness, skills, confidence, attitudes, or behaviors" (University of Wisconsin-Madison, 2021, para. 1). Due to previous local findings of the "poor conceptual understanding and awareness" of palliative care (Hawkins-Taylor et al., 2020, pg. 561), the retrospective survey was chosen to diminish response shift bias related to the variety of contexts the education would occur

and the influence of the education on the participants self-reported change between a pre/post-test survey. In other words, participants do not understand what they do not know until after they receive the education (University of Wisconsin-Madison, 2021). Since a retrospective survey was desired and there were no established retrospective surveys of palliative care knowledge and confidence in finding services, the community education team developed the retrospective survey used in this study. The survey format was based upon work by Lang and Savageau (2017). Hence, there was data collection only at one time point, after each educational event, when participants self-reported their knowledge and confidence before and after the education.

After each of the community educational events, the team member who facilitated the event documented common concerns and questions from the community members in attendance. The community education team felt it would be important to track these concerns and questions to inform future palliative care efforts within the state. Furthermore, if this study is replicated, this will also inform researchers of community members' educational needs.

Data Analysis

After the 17 events were completed, the principal investigator entered the survey data into SPSS version 27 followed by a triple check of the data entry to reduce potential errors since paper surveys were utilized. Descriptive statistical analysis was carried out on the demographic questions whereas a Wilcoxon signed rank test was performed on the retrospective questions as they are non-parametric (categorical) variables. To analyze for an association between past palliative and hospice care use and the retrospective questions, a Fisher's Exact Test was utilized as there were categorical variables with expected frequencies less than five for more than 80% of the data. A power analysis was performed before beginning the study and determined that an analytical sample

size of 28 participants was needed to provide 80% power at an alpha level of .05, one-tailed for the Wilcoxon signed rank test with medium effect size (Faul et al, 2007).

Results

Of the 256 community members who attended an educational event, 166 members completed the survey (64.8% response rate). The majority of respondents were Caucasian (93%), female (76%), older than 65 (81%), and in a married/domestic partnership, widowed, or both (81%). The majority of the events were held in rural or frontier locations; hence, only 15% of the participants and 5% of the survey respondents attended an event in an urban area, see Table 1.

Table 1

Participants and Respondents Representation from Rural and Frontier Areas

Classification of County of Event	Number of Participants (%)	Number of Survey Respondents (%)
Urban	37 (14.5)	8 (4.8)
Rural	141 (55)	107 (64.5)
Frontier	78 (30.5)	51 (30.7)
Totals	256	166

Additionally, approximately 13% of the respondents had experience with a serious health condition, 62% reported being a caregiver, and 21% reported neither having an experience with a serious health condition nor being a caregiver, see Table 2.

Table 2

Respondent Experience with a Serious Illness & Being a Caregiver

	Number of Survey Respondents (% of Respondents)	Number of Survey Respondents (% of Caregivers)
Have a serious health condition	22 (13.3%)	
Am a caregiver	102 (61.5%)	
Spouse/SO		31 (30.4%)
Parent/Guardian		27 (26.5%)
Sibling		6 (5.9%)
Friend		13 (12.8%)
Other		6 (5.9%)
More than 1 person		13 (12.8%)
Blank		6 (5.9%)
Both	5 (3%)	
Neither	35 (21.1%)	
Blank	2 (1.2%)	
Total	166	

Following the community education, participants demonstrated a statistically significant (p < .001) improvement in knowledge of palliative care and confidence in finding palliative care services with a large effect size (r = -0.54), see Table 3.

Table 3

Respondent Knowledge of Palliative Care and Confidence in Finding Palliative Care Services

	Before Education Median (SD)	After Education Median (SD)	Statistic Z	*p*-value	Effect *r*
Knowledge	.8856 (.96455)	2.1272 (.88045)	-9.679	< .001	-0.547089
Confidence	.77 (.944)	2.03 (.962)	-9.552	< .001	-0.543394

Note. N=166; Wilcoxon signed-rank test

Fisher's exact test was conducted to determine if there was a significant association between palliative care knowledge and confidence in finding palliative care services with past experience receiving palliative or hospice care services. If the respondent or one of their family members had received palliative care services previously, there was a statistically significant association with palliative care knowledge and confidence in finding palliative care services (two-tailed, $p < .001$). If the respondent or one of their family members had received hospice care services previously, there was a statistically significant association with confidence in finding palliative care services ($p = .012$) and three of the four questions related to palliative care knowledge ($p = .002, .013, .016, .052$), see Table 4.

During the discussion after the educational material was provided, participants brought forward concerns and questions related to the presentation. Common concerns centered around keeping people in their homes independently and caregiving for others. These concerns were focused on the lack of resources to accomplish those goals.

Table 4

Association between Palliative and Hospice Care Services with Palliative Care Knowledge and

Confidence in Finding Palliative Care Services

Survey Question	Palliative Care Services *p*-value	Hospice Care Services *p*-value
Knowledge of Palliative Care		
How palliative care can provide support to a person facing a serious illness	< .001**	.013*
How palliative care can provide support to a caregiver of a person facing a serious illness	< .001**	.052
The types of services offered through primary palliative care	< .001**	.016*
Difference between palliative and hospice care	< .001**	.002*
Confidence in Finding Palliative Care Services		
Where to find palliative care services if needed.	< .001**	.012*

Note. Fisher's Exact Test. *Statistically significant at *p* < .05, two-tailed. **Statistically significant at *p* < .001, two-tailed.

Community members reported a lack of home health, hospice, and long-term care overall but

especially in the rural and frontier areas.

Common questions arose surrounding advance care planning as well as palliative and hospice

care. Community members were curious where to obtain advance care planning documents, how

to start conversations with family, and who (persons or organizations within the community) could

help complete the documents. Furthermore, participants asked for information on where to find a

Notary. For palliative care, there was uncertainty on where to find and how to access palliative care services as well as differentiating outpatient and inpatient services. The main questions regarding hospice care were to better understand the Medicare hospice benefit, the dying process, and several questions arose about dementia at the end-of-life.

Discussion

The purpose of this study was met as participants had a significant increase in self-reported palliative care knowledge and confidence in finding palliative care services after attending the education event. Not surprisingly, if the participants had previously used palliative care services, their self-reported knowledge of and confidence in finding palliative care services was significantly higher than those who had not used palliative care services. If they had used hospice care services previously, participants had higher self-reported knowledge related to differentiating palliative and hospice care as well as understanding how palliative care supports person with serious illness, types of primary palliative care services, and where to find palliative care services. However, they did not have higher self-reported knowledge of how palliative care supports the caregivers of persons with serious illness.

Enhancing the public's knowledge of palliative care fostered interesting discussion in rural communities. Presenters shared the differences between primary and specialty palliative care which led to discussion of home health, hospice, Meals on Wheels, and other supportive services in the area. Workforce challenges and declining health of the elderly population were some of the concerns voiced by participants as to how those struggling with serious health conditions could stay in their community. Several smaller communities did not have access to home health and hospice services and felt this would take priority over palliative care. Through discussion with the

participants, local primary palliative care services were identified which in many cases included their primary care provider offering palliative care services.

The community education team quickly realized presenting at an established meeting, such as a noon meal or a monthly meeting, increased attendance. Events that were advertised solely to share about palliative care had significantly less attendees. This may have been due to the challenges associated with participants leaving home or lack of understanding of palliative care.

Lastly, lack of technology was a challenge early in the process. The community education team had a well-prepared PowerPoint but it was quickly discovered that most facilities in rural areas were not equipped for this. As it turned out, the presenters found the audience to be more engaged and saw a richer discussion when presenting in a conversational style. Additionally, the team learned they earned respect from community members if time was taken to sit down and share a meal with the group prior to presenting. Taking the time to know the organization, the audience, and the venue paid off with better engagement and dialogue.

The community education team saw value including local healthcare professionals to introduce to the community as a resource to share expertise. The intention was to acquaint participants with the local providers and assure a common message was shared with the community. Having a local provider present was extremely valuable in addressing questions focused on community resources, advance care planning, and end of life care.

Workforce challenges and lack of access to home health and hospice make palliative services a luxury that rural residents cannot comprehend. However, rural residents want to remain in their home, or at least their communities, and their caregivers want local resources to honor those goals. With over half of the participants identifying as a caregiver to someone with a serious illness, this

latter need was very apparent. Participant questions focused on advance care planning and hospice care which could be future directions of community education.

Limitations

The retrospective survey entails participants self-reporting their knowledge and confidence which may not provide a reliable measure of actual knowledge and confidence. Social desirability may also influence the participants rankings since they may report an increase in knowledge and confidence, knowing that is the desired outcome. Additionally, our sample is homogenous being mostly Caucasian, female, and older than 65. Future research should address these limitations.

Conclusion

In-person community education was beneficial in increasing community members' knowledge of palliative care and how to access primary palliative care services. Additionally, needs were identified that will play an important role in providing care in a manner respectful of the goals of rural community members. As the rural population ages, it seems evident that caring for those with serious illness(es) and supporting caregivers will become of greater importance. Educating and listening to these individuals will be critical in providing resources and care congruent with their goals.

Conflicts of Interest

These authors declare no conflicts of interest.

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