

Quality Measures for Community-Based, Rural Palliative Care Programs in Minnesota: A Pilot Study

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Abstract

Background: Despite the growth of palliative care programs in many urban areas, palliative care programs remain less common in rural communities. As more community-based programs emerge, particularly in rural areas, it will be important to establish a standard set of quality measures that are useful for improving care and feasible for program evaluation.

Objectives: The study's objective was to identify and field test a standard set of quality measures for rural, community-based palliative care programs that reflect clinical quality, patient and family experience, and impact on inpatient and emergency department utilization.

Methods: A pilot program was conducted to test standardized quality measures for rural, community-based programs. Measures were identified through review of existing measures and input from experts in palliative care and rural health services. The study was carried out in 2012 and 2013 in five community-based palliative care programs from rural communities. A total of 138 palliative care patients were included. Measurements were chart abstraction, patient and family experience surveys, patient-level health care utilization, and program-level operations surveys. Phone interviews with each participating program were performed at the study's end.

Results: The participating programs found the measures feasible to collect, and the information they provided aided in assessment, comparison of structure, and process improvement for care delivery. Program staff suggested additional potential measures and expressed their desire to track the measures beyond the pilot time frame.

Conclusion: The standard measures developed and tested were deemed feasible to collect and useful for all five participating rural, community-based palliative care programs.

Introduction

PALLIATIVE CARE PROGRAMS are well established in large, urban hospitals, but less so in community-based or rural settings. The importance of extending palliative care to these settings is rooted in the benefits these programs can provide. Palliative care has been shown to be associated with improved quality of life and improved emotional and psychological well-being,¹⁻⁴ cost savings,⁵⁻⁷ and even extending life in some instances.^{3,8} Given that patients in rural communities are often disproportionately elderly and chronically ill,⁹ palliative care programs could potentially provide a significant contribution to the overall health and well-being of these communities. Despite the challenges inherent in providing palliative care in

rural settings, including scarce resources, limited training and experience with palliative care, and geography,¹⁰⁻¹² previous studies have demonstrated that establishing programs in these settings is feasible.^{1,13-16}

As rural and community-based palliative care programs continue to emerge, it will be important to establish meaningful and feasible quality measures. Ideally, quality measures provide a standard for programs across settings and allow comparison and benchmarking. Although quality measures from hospital-based palliative care programs can provide guidance, they are relatively new or have not been fully developed.¹⁷⁻²⁰ Hospital-based measures are not always appropriate for community-based and rural programs. Standardized measures for community-based programs are

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Accepted April 16, 2015.

almost nonexistent. The objective of this study was to identify and field test a standard set of quality measures for rural, community-based programs that reflect clinical quality, patient and family experience, and resource utilization as a metric of financial impact.

Methods

This study was conducted in five rural communities of Minnesota during 2013 by Stratis Health, a nonprofit organization that focuses on leading collaboration and innovation in health care quality and safety. Key members from Stratis Health and an expert from the field with extensive experience in palliative care program development served as the study team.

Invitations to participate in this study were sent to 14 rural, community-based palliative care programs in Minnesota in June of 2012. Invitations were issued based on participation in previous rural palliative care work. Six rural programs volunteered as pilot sites, although one of the programs later withdrew due to participation in another initiative that included patient surveys. A total of five palliative care programs participated in the study (see Table 1), four in central and northern Minnesota and one in western Minnesota. The 2012 populations of the communities where the programs are located ranged from 1517 to 7777,²¹ in counties with an average population density of 43 per square mile.²² Four of the communities were served by a critical access hospital (25 beds or less) and one by a small prospective-payment system hospital with fewer than 50 beds. Each program was unique in its structure and processes for providing palliative care services.

The development of measures involved several steps. First, the study team reviewed existing guidelines and measures, including the National Quality Forum (NQF),^{23,24} the Alliance of Community Health Plans,²⁵ Assessing Care of Vulnerable Elders,²⁶ and recommendations from the Center to Advance Palliative Care. The review focused on four measurement domains: structure, clinical quality, the experience of the patient and/or their family, and health care utilization. The domains were based on published literature,^{20,27,28} and in part, the concepts of the Triple Aim, which focuses on increasing quality and patient experience in health care while lowering costs.²⁹ From this review, a list of measures was drafted and reviewed by a technical advisory panel comprised of nationally recognized experts in the fields of palliative care and rural health services. The measures attempted to incorporate existing quality metrics from the field while maintaining feasibility for community-based palliative care programs. Data collection tools were developed for the

measures and suggested for testing by the advisory panel. Clinical measures were chosen from the NQF Endorsed Measures for Palliative Care and End-of-Life Care Measures.³⁰ A list of measures is available in Table 2.

Project design and data collection

The project design and data collection methods described below were reviewed and approved by the Minnesota Department of Health institutional review board.

In order to collect data regarding the structure and process of the participating programs' palliative care services, a short operations survey was developed by the study team. The survey included program elements common in palliative care programs and was administered at the beginning and end of the study period. Program elements reported included level of training and/or certification in palliative care among palliative care staff as well as processes for after-hours support, such as availability of a clinician for symptom management. Programs reported whether processes to facilitate completion and documentation of advance directives were in place.

To assess patient perception and satisfaction with the palliative care program, the National Hospice and Palliative Care Organization's Family Evaluation of Palliative Care survey³¹ was adapted to allow responses by either the patient or their family. These patient and family experience surveys were administered 30 to 60 days after admission to the program to obtain information from those who received both an initial visit and at least one follow-up visit with the program.

A Microsoft Excel-based tool was adapted to collect and calculate clinical and utilization measures. This tool, The Hospice AIM Toolkit, was created by the organization IPRO in 2010 as part of a Quality Improvement Organization Special Study conducted on behalf of the Centers for Medicare & Medicaid Services. Programs enter patient-level data abstracted from medical records and the tool then automatically calculates hospice measures. Because many of the measures from this tool were similar to the measures developed for this study, the study team requested permission from the developer and adapted the tool to reflect the patient-level data elements and measures tested in this study. The software necessary to use the tool (Microsoft Excel) was already in use at each of the participating palliative care programs, allowing each program to collect the necessary data and calculate measure results for immediate feedback.

The study team developed informational and training materials to assist the programs in the use of the tools and data collection and submission. These materials included detailed

TABLE 1. DESCRIPTIONS OF PALLIATIVE CARE PROGRAMS PARTICIPATING IN THE PALLIATIVE CARE MEASUREMENT PILOT

Site A	Provides services across the continuum of care under the umbrella of a small independent integrated delivery system. Program coordinator is an RN based in the hospital.
Site B	Provides services for home care clients. Program coordinator is an RN at a home care and hospice agency affiliated with a large integrated delivery system.
Site C	Provides services through home care and/or in the hospital and nursing home of a small independent integrated delivery system. Program coordinator is an RN based in home care.
Site D	Provides services for home care clients. Program coordinator is an RN at a home care and hospice agency affiliated with a large integrated delivery system.
Site E	Provides services for patients at the clinic, nursing home, and through home visits. Program coordinator is a social worker based in the hospital.

TABLE 2. DRAFT MEASURES FOR PALLIATIVE CARE MEASUREMENT PILOT¹

<ul style="list-style-type: none"> • Percentage of palliative care patients who were screened for pain during the palliative care initial encounter • Percentage of palliative care patients who screened positive for pain and received a clinical pain assessment within 24 hours of screening • Percentage of palliative care patients who were screened for dyspnea during the palliative care initial encounter • Percentage of palliative care patients who screened positive for dyspnea who received treatment within 24 hours of screening • Percentage of palliative care patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss
<p>Additional indicators/demographic categories</p> <ul style="list-style-type: none"> • Primary diagnosis group • Reason for initial patient consultation • Reason for patient discharge • Breakdown of palliative care patient housing/living situation
<p>Utilization information</p> <ul style="list-style-type: none"> • Average number of inpatient stays six months prior to beginning palliative care • Average number of emergency department visits six months prior to beginning palliative care • Average inpatient days six months prior to beginning palliative care • Average number of inpatient stays and days since starting palliative care (only for patients receiving services for at least 60 days) • Average number of emergency department visits since starting palliative care (only for patients receiving services for at least 60 days)

¹Based on the National Quality Forum Endorsed Palliative and End-of-Life Care Measures.

data specification dictionaries for the tools. A training webinar was held in January of 2013 with the five participating programs. Throughout the study, Stratis Health provided ongoing technical assistance for the patient-level data collection and submission, and tracked issues with data definitions and use of the Excel tool. The participating programs were provided with comparison reports reflecting individual and aggregate data from participating programs after each data collection period.

Data from the patient-level clinical and utilization tool were submitted to Stratis Health on a quarterly basis. In order to ensure privacy of patient data, information was de-identified at the collection site through a report function built into the tool that removed personal health information and created a report for submission. The patient and family experience surveys were distributed by the individual programs and returned directly to Stratis Health via self-addressed postage-paid envelopes. In the comparison reports provided to the programs, program-identified data were only shared with each respective program, while aggregated comparison data were shared across all five participating programs.

Semistructured phone interviews were held with the participating programs after the final data submission to gather feedback on the utility of the measures and the feasibility of data collection. The study team prepared several documents for the technical advisory panel to review to inform their feedback. Documents included data reports, interview summaries, and data collection tools.

The final versions of the tools and training resources are available from Stratis Health by visiting www.stratishealth.org/PCmeasures.

Results

All five participating programs completed the operations survey regarding the staffing and resources for their program. At the beginning of the study period, two of the five programs

had a board-certified palliative care physician and two had a registered nurse (RN) who was board-certified in palliative nursing. All five programs had access to a social worker and chaplain, both of whom with varying amounts of training in palliative care. Processes regarding communication across care settings to identify and/or support completion of advance directives were in place in all participating programs.

Data on pain and dyspnea were collected following specifications for the NQF Endorsed measures related to those two physical symptoms.³⁰ For the two pain measures, data elements collected included the number of patients who were screened for pain during the palliative care initial encounter, and for those who screened positive, the number who received a clinical assessment of pain within 24 hours. Among all programs, the percentage of new palliative care patients screened for pain ranged from 65% to 84%, and of those who screened positive for pain, 60% to 77% received a clinical assessment within 24 hours. The two dyspnea measures were calculated using the number of patients who were screened for dyspnea during the palliative care initial encounter, and for those who screened positive, the number of patients who received treatment within 24 hours of screening. Across participating programs, 54% to 72% were screened for dyspnea during the initial encounter, and between 50% and 89% received treatment within 24 hours. An additional clinical measure that addressed spiritual assessment was chosen from the NQF Endorsed measure set. Data collected for this measure included the number of palliative care patients with documentation in the clinical record of a discussion of spiritual or religious concerns, or documentation that the patient or caregiver did not want to discuss it. The percentage of new palliative care patients with a discussion about spiritual concerns documented ranged from 56% to 85%.

The most common reasons for the initial palliative care consult included goals of care (79%), psychosocial support (78%), pain or other symptoms (55%), and advance care planning (41%). Results indicated that most consults were

TABLE 3. SUMMARY OF PALLIATIVE CARE MEASUREMENT PILOT PATIENT EXPERIENCE SURVEY RESULTS

Question	Response category, n (%)				
	Always	Usually	Sometimes	Never	N/A
Q1 The Palliative Care Team treated everyone involved with my care respectfully	25 (86)	4 (14)	0 (0)	0 (0)	0 (0)
Q2 The Palliative Care Team kept me informed about the likely outcome of care	23 (79)	5 (17)	0 (0)	0 (0)	1 (3)
Q3 The Palliative Care Team kept my family informed about the likely outcome of care	24 (83)	2 (7)	0 (0)	0 (0)	3 (10)
Q4 The Palliative Care Team provided emotional support for me	23 (79)	6 (21)	0 (0)	0 (0)	0 (0)
Q5 The Palliative Care Team provided emotional support for my family	19 (65)	6 (21)	0 (0)	0 (0)	4 (14)
Q6 The amount that the Palliative Care Team focused on my pain control was good	25 (86)	4 (14)	0 (0)	0 (0)	0 (0)
Q7 ¹ The Palliative Care Team addressed other symptoms (such as constipation, breathing, sleep, nausea, etc.)	24 (86)	3 (11)	1 (4)	0 (0)	0 (0)
Q8 I was satisfied with the competence of the Palliative Care Team	28 (97)	1 (3)	0 (0)	0 (0)	0 (0)
Q9 I was satisfied with the concern the Palliative Care Team had for me	28 (97)	1 (3)	0 (0)	0 (0)	0 (0)
Q10 Overall I received the best possible care from the Palliative Care Team	28 (97)	1 (3)	0 (0)	0 (0)	0 (0)
Q11 After receiving palliative care, I would recommend it to others in need of palliative care	28 (97)	1 (3)	0 (0)	0 (0)	0 (0)

¹Denominator for Q7 is n=28; all other denominators are n=29.

requested for more than one reason. The majority of patients discharged from palliative care services were either admitted to a hospice program or died while receiving palliative care (data not shown).

The response rate for the patient and family experience surveys was 42%, with program-specific response rates ranging from 35% to 80%. The survey responses were overall positive, with responses either “Always” or “Usually” in every case except one. These ratings demonstrated satisfaction with pain management, emotional support, respectful communication, and overall satisfaction with the program. Due to the limited size of the population surveyed, the study

team did not collect data on whether surveys were completed by the patient or the family member. Table 3 contains a summary of the responses from the surveys received.

The resource utilization measures were collected to address the financial impact of the programs, from potential cost avoidance through lower utilization of inpatient and emergency department services. During every interval measured, the average utilization of hospital-based care (inpatient stays, days in the hospital, ED visits) was lower after the initiation of palliative care than six months prior to initiation (see Figs. 1–3). Costs of the palliative care programs themselves were not evaluated.

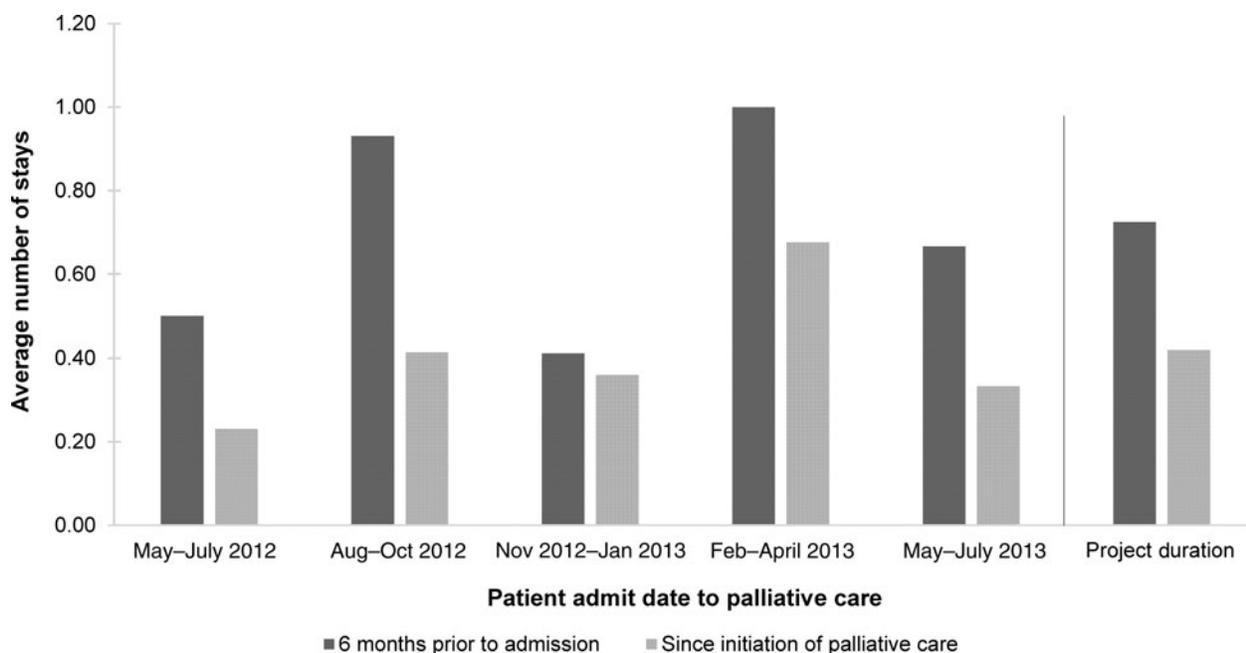


FIG. 1. Average inpatient stays per Palliative Care Measurement Pilot patient.

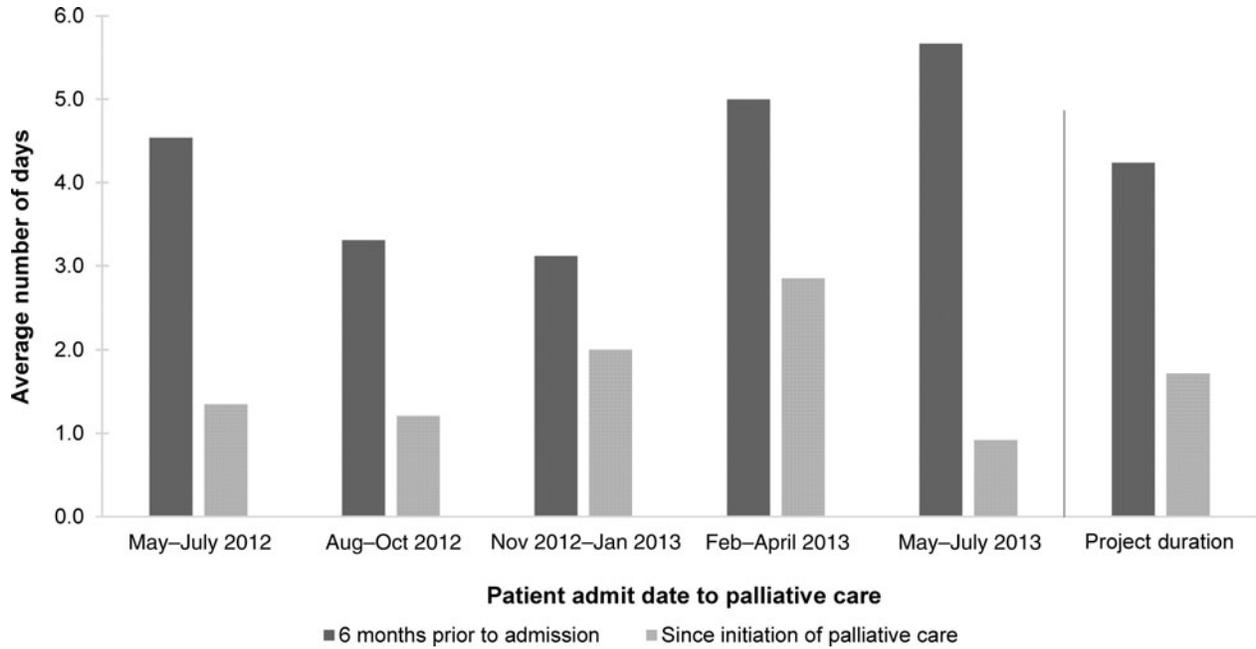


FIG. 2. Average inpatient days per Palliative Care Measurement Pilot patient.

Feedback from the participating programs obtained during the phone interviews indicated that the operations survey helped them identify disciplines or roles missing from their teams, which led to staffing and process changes. Feedback from program staff also included several suggestions for improving the current measures and for potential additional measures. Typically, suggestions for improving current measures involved additional options for response categories, clarification of possible responses, or the ability to add more detail to responses. For example, programs indicated that it would be useful to expand the options for why a patient ended services. Programs recommended the addition of psychoso-

cial measures (e.g., anxiety, depression) as well as a measure to track referrals made to community resources and services. Programs also indicated their desire to track outcomes over a longer period of time.

Discussion

The study achieved its objective of identifying and testing a set of standard measures in rural, community-based palliative care programs. The measures were deemed useful by the programs, and the feasibility of collecting the measures was demonstrated. Even though the participating programs

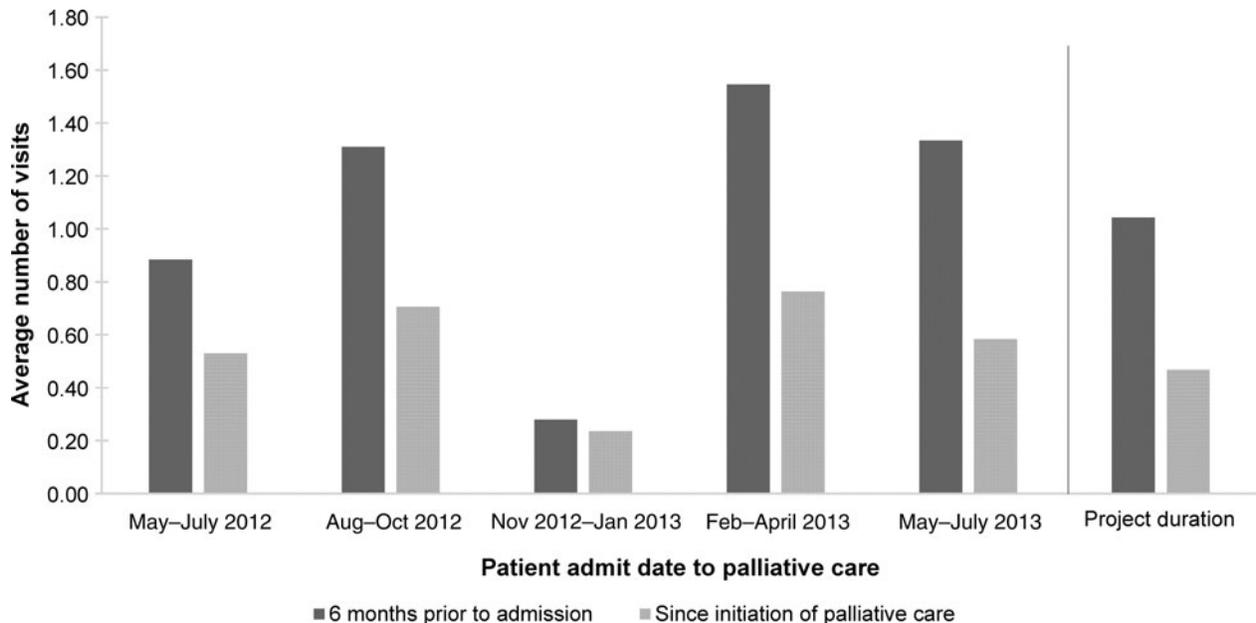


FIG. 3. Average emergency department visits per Palliative Care Measurement Pilot patient.

varied in their structure and process of care delivery, each found collecting standard measures useful for the evaluation and improvement of care, suggesting that these measures may be valuable for a variety of rural and/or community-based programs. Several programs involved in this study indicated that the data collected helped to standardize and coordinate the processes involved in providing palliative care. This may demonstrate the important role standard measures play in supporting integration and communication, which have previously been suggested to be key factors in the success of rural palliative care programs.^{32,33}

The introduction of standard measures to the five participating programs provided specific benefits to those involved. The programs indicated that the information collected from the operations survey was internally useful to track progress and inform administrators of the operational elements that are an integral part of a palliative program. They indicated that it was helpful to see and compare their results with those of the other participating rural programs. Program staff reported that the patient and family survey fully captured the palliative care experience, but indicated that additional questions specific to their program would be helpful. In at least one case, the measures helped a program to identify opportunities for improving processes and documentation (specifically, in response to results of pain screening and assessment), which led to focused quality improvement efforts in that area.

For future development, in addition to the ability to track information over time, programs suggested addressing psychosocial needs, as the current NQF measures primarily addressed physical and spiritual aspects of care. Because of the lack of an NQF-endorsed measure specific to the psychosocial domain, this aspect of care was not addressed in this pilot. Goals of care discussions and psychosocial needs were the two most frequently cited reasons for palliative care consultations in the participating programs, further supporting the need for this type of metric. Programs also indicated that one of their key roles is to help connect patients with programs and community resources related to social service needs (e.g., Meals on Wheels) and recommended a measure to capture that aspect of their services. This type of measure regarding involvement and collaboration with the surrounding community may also be appropriate, as the recent report from the Institute of Medicine on end-of-life care describes the inclusion of social services and emphasizes the need for public education and engagement with palliative care programs.³⁴ Information on health care utilization was deemed to have good potential as a measure, although in this study, utilization results were relatively unreliable due to the small populations. Utilization was difficult to track consistently for some programs because of a lack of access to records across care settings due to different medical record systems. However, one program was able to leverage their utilization data to inform conversations with payers regarding the value of services they provide. The participating programs indicated that in the future they would like to explore alternative data sources or methods for measuring utilization in order to provide further evidence for the value palliative care programs provide.

Limitations to this study should be noted. First, the five participating programs represent a fraction of rural palliative care programs in one state, and the number of patients from those programs produced a limited sample size, which was

further deteriorated by the relatively low survey response rate. Secondly, the participating programs had varying structures and operational processes that may not align with other community-based programs, even though the varied structures of the pilot programs did not appear to impact feasibility or results. Finally, while demographic or socioeconomic information was not collected, the population of the areas where the communities are located is relatively ethnically homogeneous and therefore does not allow for generalization of the results to different parts of the country. However, given that the measures revolve primarily around provider processes, the racial/ethnic makeup of treated patients may not have much of an impact on their effectiveness. Lastly, further refinement of the measures would be important. For example, this may include measuring the severity of dyspnea and resultant treatment, or delineation of patient or family response to the satisfaction survey.

In conclusion, the standard measures developed and tested were deemed to be feasible and useful for five participating community-based, rural palliative care programs, and lay the groundwork for development of measures as community-based palliative care evolves.

Acknowledgments

We are grateful for the five rural palliative care programs that participated in this project from the following Minnesota communities: Fosston, Madison, Mora, Staples, and Wyoming. Their dedication to their patients and pioneering spirits made this work possible. This project was funded by UCare.

Author Disclosure Statement

No competing financial interests exist.

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