



National Rural Health Association Technical Assistance Project Final Report

Rural Palliative Care Pilot Project

September 29, 2009

Stratis Health, based in Bloomington, Minnesota, is a nonprofit organization that leads collaboration and innovation in health care quality and safety, and serves as a trusted expert in facilitating improvement for people and communities.



Acknowledgements

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Executive Summary

The National Rural Health Association (NRHA) received funding as part of a grant from the Health Resources and Services Administration - Office of Rural Health Policy (HRSA - ORHP) to provide technical assistance to up to five communities. NRHA contracted with Stratis Health to support this effort. To be most efficient with the funding available, the potential areas of assistance were narrowed to three topic areas where Stratis Health had existing resources and expertise to draw upon. In early 2009, the Technical Assistance Advisory Committee for the project selected a focus on *Community Oriented Planning for Palliative Care*.

After recruitment, application, and review, process, Stratis Health selected three rural communities to participate in the pilot project:

- Franklin, NC (led by Angel Medical Center)
- Ruleville, MS (led by North Sunflower Medical Center)
- Valley City, ND (led by Mercy Hospital)

Each Community Team participating in the NRHA Rural Palliative Care Pilot Project completed an initial needs assessment aimed at identifying the resources, needs, and opportunities in their community for palliative care processes such as advance directives, linkages to community resources to facilitate continuity of care, improving pain and symptom management, or goals of care discussions with patients and family members. In-person day-long community capacity building sessions with education and action planning for palliative care were held with each community team in July, facilitated by Stratis Health. Formal technical assistance calls were held with each community team twice during the project. A final call for all three community teams and for the Advisory Committee was held on September 28th as part of a wrap-up for the formal project.

Results and Recommendations

All three participating communities were able to form a community-based team from multiple care settings and develop an action plan related to palliative care processes. Two teams focused their efforts on Advance Directives, the third community focused on linkages between agencies that could provide services, and developing a 'Care Captain' program with volunteers to support patients with complex care issues. Each team had unique characteristics and challenges which impacted their joint efforts, yet each made significant progress towards implementation of their action plans and all three have intentions of continuing efforts after the end of the pilot project.

The findings of this pilot project reaffirm the belief that rural communities are uniquely positioned to meet the challenges of providing palliative care through collaborative efforts. A set process and timeline, access to palliative care program development expertise, and external facilitation to help initiate and develop community-based teams are important aspects that can assist in further development of community based palliative care efforts in rural areas.

Based on the pilot project results and experience, Stratis Health recommends expanding the pilot to reach additional rural communities, with adaptations based on the lessons learned from the pilot.

Background and Topic Selection

The National Rural Health Association (NRHA) received funding as part of a grant from the Health Resources and Services Administration, Office of Rural Health Policy (HRSA - ORHP) to provide technical assistance to up to five communities. One of the goals of this activity was to pilot technical assistance efforts to help identify potential areas of focus for rural health initiatives in the future.

NRHA contracted with Stratis Health to support this effort. To be most efficient with the funding available, the potential areas of assistance were narrowed to three topic areas where Stratis Health had existing resources and expertise to draw upon.

Stratis Health recruited a Technical Assistance Advisory Committee to assist in topic selection and in providing guidance for the effort (Appendix A – Advisory Group Roster). The three potential areas of technical assistance included:

- Emergency Department Measure Collection and Improvement
- Electronic Health Record (EHR) Planning Assistance
- Community-Oriented Planning for Palliative Care

In early 2009, the Technical Assistance Advisory Committee selected a focus on Community Oriented Planning for Palliative Care. Some of the rationale behind this selection included:

- Many rural communities are well poised to focus on community-based palliative care, but technical assistance and resources for support in this area are not readily available.
- Palliative Care is an area of increasing importance and had been recently identified as one of six national priorities by the National Quality Forum's sponsored National Priority Partnership. The National Quality Form has also developed a *National Framework and Preferred Practices for Palliative Care and Hospice Care Quality*¹ which could be used to help guide the project.
- The focus on community capacity for palliative care was a broader option than the other topics which focused technical assistance at a specific facility level (hospital and/or clinic).

Titled the *NRHA Rural Palliative Care Pilot Project*, the goal of the six-month initiative was for participating communities to build capacity to develop a community team, assess need for palliative care services, and develop an action plan on an area of focus related to palliative care processes such as advance directives, linkages to community resources to facilitate continuity of care, or improving pain and symptom management. The recruitment and application process kicked-off in late March 2009, with communities selected and beginning their needs assessment work in May 2009. On-site education and planning meetings were held in July. Technical Assistance calls were held in May/June and August. A final call, with the three communities sharing their efforts and progress with each other was held in late September 2009. Individual consultation and support by phone and e-mail was also provided to each team as needed during the length of the project (Appendix B - Timeline).

¹ NQF,2006. Executive Summary can be downloaded at:

www.qualityforum.org/Publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx

Implementation

Recruitment and Application Process

Stratis Health worked with the Technical Assistance Advisory Committee members to recruit potential communities for participation in the pilot project. Potential communities were required to identify a community-based team and complete an application which included information about palliative care services and community team readiness.

Five community applications were received, and Stratis Health staff reviewed and scored the applications to select the three participating communities:

- Franklin, NC (led by Angel Medical Center)
- Ruleville, MS (led by North Sunflower Medical Center)
- Valley City, ND (led by Mercy Hospital)

Notification letters were sent to all communities that applied. A welcome packet was sent to each participating community that included a press release that could be customized and used to promote the effort in their local press.

Community Needs Assessments

Each Community Team participating in the NRHA Rural Palliative Care Pilot Project was required to complete a needs assessment aimed at identifying the resources, needs, and opportunities in their community for palliative care services. Community Teams were requested to complete the needs assessment survey as a team to assist in gathering perspective from across the spectrum of participants, and begin discussions about key areas for focus.

After completion of the needs assessments, Karla Weng, the program lead from Stratis Health, and Lyn Ceronisky, Director of the Fairview Palliative Care Leadership Center and a palliative care program and development consultant, completed technical assistance conference calls with each community team to review and discuss the needs assessments and assist them in narrowing towards an area of focus for this effort.

In Person Education and Planning Sessions

Each community team was requested to meet at least once prior an on-site visit by Stratis Health staff in July. Teams were provided a discussion guide to assist with meeting planning, and encouraged to prioritize one to three areas of focus on which they would develop an action plan. The 38 Preferred Practices for Palliative and Hospice Care Quality developed by the National Quality Forum were used to help guide for communities when identifying potential areas of focus.

In-person day-long community capacity building sessions were held with each community team in July. Karla Weng from Stratis Health facilitated each session, with palliative care program

and development consultant Lyn Ceronsky, joining the discussion for part of the day by phone. The agenda included education on palliative care, models of collaboration, and quality improvement processes, as well as a focus on development of an action plan for the selected area of focus by each community.

The in-person sessions in each community included good representation across the community teams, and the session evaluations were positive. At each session a NRHA Technical Assistance Advisory Group member and/or state level contact was able to participate in the in-person meetings and it was found valuable to have their state-level perspective and insight as part of the discussion. (Jody Ward from University of North Dakota attended in Valley City, Brock Slabach from NRHA attended in Ruleville, Judy Brunger from the Carolina Center for Hospice and End of Life Care attended in Franklin).

Technical Assistance Calls and Individual Assistance

Formal technical assistance calls were held with each community team twice during the project. The first call was held after the needs assessments were completed in late May/early June. Another call was held with each team in August to assess progress, answer questions, and assist in identifying resources. Multiple individuals from each community team typically participated on the technical assistance calls. Stratis Health followed-up after each call with resources and/or materials as identified during discussion with each team.

Karla Weng and project consultant, Lyn Ceronsky, each also supported the community teams by responding to several e-mail and/or phone questions throughout the effort by identifying resources and/or tools as appropriate. Community teams were also directed to the Stratis Health MN Rural Palliative Care Initiative website for which contains a wide variety of resources and tools related to rural palliative care (www.stratishealth.org/palcare)

Final Conference Call and Evaluation

A final conference call for all three community teams and for the Advisory Committee was held on September 28th as part of a wrap-up for the formal project. Each team shared information about their efforts and offered thoughts on what aspects of the project were most helpful to their community team. Each community team also completed a written evaluation of the pilot project.

Results

All three participating communities were able to form a community-based team from multiple organizations and develop an action plan related to palliative care processes. Two teams focused

their efforts on Advance Directives, the third community focused on linkages between agencies that could provide services for people with advanced illness, and developing a ‘Care Captain’ program with volunteers to support patients with complex care issues. Each team had unique characteristics and challenges which impacted their joint efforts, yet each made significant progress towards implementation of their action plans and all three have intentions of continuing efforts after the end of the pilot project. A summary of each team’s activities is outlined below:

Franklin, NC

The Franklin team included representatives from across the care spectrum including hospice, home health, hospital, physician office, public health, long term care and assisted living. The team agreed that a focus on Advance Directives would be helpful in their community as there is not currently a consistent process in place across organizations to track and share completed Advance Directives. Franklin is a retirement locale, with many older community members who do not have family in the area. Thus the team also intends to focus education about Advance Directives to include the importance of working with family members to ensure they are familiar with the individual’s desires.

Activities completed on Franklin’s action plan to date include:

- Reviewed current advance directive forms in use in the community, and NC state regulations regarding Advance Directives. Decided not to identify a singular form for use, but promote any form that meets state requirements. North Carolina does require that advance directive forms are notarized.
- Developed education/outreach plan including working with local churches, banks, senior service center, and service clubs to provide community education and opportunities to complete an Advance Directive. Will also look for opportunities where a notary is available to notarize forms once completed.
- Looking into options for internet completion, storage, and communication of Advance Directive forms. Also assessing potential for video education available at physician offices with materials and information on completing advance directives.

Next Steps:

- Develop plans/process for coordination and communication of completed advance directives between levels and sites of care.
- Implement education plan.
- Monitor proportion of completed advance directives across care settings and adjust plans if not seeing anticipated increases. (For example: home health currently sees advance directives in 20% of patients, goal is to have that to 30% by the end of 2009.)

The Franklin team has also submitted a Network Planning Grant to the Office of Rural Health Policy which would allow them to develop a formalized “Macon County Palliative Care Team” with the ultimate goal of having the ability to see patients for palliative care consults with support/resources coming from team members across the network. The goal of this initiative is that care across the continuum of sites is delivered in concordance with patient wishes.

Ruleville, MS

The Ruleville team includes representatives from the hospital, clinic, long term care, and home health agency. At this point, all the participating organizations are under the umbrella of North Sunflower Health Center. The team has invited two independent hospice agencies and an independent long term care center in the community to participate, but at this time has not found these agencies receptive to a joint effort.

The Ruleville team has decided to focus efforts on Advance Directives, in particular, the completion and sharing of Advance Directives across their system. They plan to start their efforts with staff education for all employees of North Sunflower Health Center (around 300). They will be encouraging and providing support for all staff to complete their own Advance Directive. This is an important component of implementation for the process of increasing Advance Directive use, but also is a key outreach effort as many employees have family and elderly relatives in the area. The goal of this Advance Directive focused initiative is that care across the continuum of sites is delivered in concordance with patient wishes.

Activities completed on Ruleville's action plan to date include:

- Multiple education sessions for the team around advance directives including legal aspects.
- Reviewed several advance directive forms and decided to continue to utilize their current form.
- Developing process for communication of completed Advance Directives across the system. Will start with keeping paper forms in the hospital social work department. Will revisit as part of EMR implementation over the next year.
- Planning for staff education in October, and roll-out to swing bed patients in November.

Next steps:

- Implement staff education and completion of staff Advance Directives in October.
- Start working with swing-bed patients to complete Advance Directives in November.
- In December, review processes and make adjustments. Consider plan for rolling out to additional areas.
- In January, re-focus efforts on engaging area hospice agencies and the other long term care facility in town.
- Early 2010 begin community education at health fairs. Consider having a table with resources and information available at the clinic and working with the chronic disease program to incorporate advance directive completion into their processes.

Valley City, ND

The Valley City team includes representatives from the hospital, home health, hospice, public health, regional aging services and local adult services. A representative from the hospital's corporate office (CHI) has also been participating and offering support to the team. The team identified that they would like to focus efforts on those patients that could benefit from hospice

services, but don't meet the criteria for hospice, and provide assistance to linking them to the multitude of resources available for support in their community. They are also exploring the idea of having volunteer Care Champions that could assist patients by offering transportation, attending appointments, and assisting in communication.

Activities completed on Valley City's action plan to date include:

- In process of defining criteria for patients that will be referred to the program. Initial plan is to enroll ten patients, one from each physician in the community.
- Developing referral form for providers to utilize
- Developing flow chart (or 'service wheel') of what services each group can offer and how best to link patients into those services.
- Working with *Faith in Action* program to identify volunteers that will be trained as Care Champions. Care Champions will provide transportation, attend visits with patients, and assist with communication to increase patient understanding of physician conversations.
- Developed draft brochure to share with Medical Staff at October meeting which will be used to explain the program to providers and potential patients.
- Three team members participated in facilitator training and are starting to offer six-week "Living Well" programs for community members with on-going health problems focusing on skills and self-management strategies.

Next steps:

- Present to Medical Staff in October to get feedback/buy-in to begin referral process.
- Complete 'flow chart' and identify process for how to intake patients into the program once referred.
- Develop training for Care Champions and refine draft set of questions and responsibilities the Care Champions can utilize as a tool.
- Start enrolling and supporting patients starting January, 2010. Review progress and processes late spring/early summer 2010 and make adjustments as needed.
- Work with Public Health Agency to understand how recent grant focusing on chronic disease management can help support/link to palliative care efforts.

Feedback from participating teams

In addition to participating in the final call, all three teams completed a written *Community Team Evaluation* of the project. One community had each team member complete the evaluation and provide aggregate comments. In the other two communities, the team leader completed the evaluation.

Overall, the evaluation of the program and services provided was positive. On a scale from one to four, with four being the highest, two teams indicated a four, and one team indicated a three when asked if they would encourage other communities to participate in a similar effort.

All three teams indicated the in-person educational and planning workshop was the most instrumental to assisting their community teams. All aspects of the services provided ranked

high, but the technical assistance calls and the follow-up with resources/tools were also called out as particularly useful.

To improve the program, teams recommended a longer timeline, clarification of expectations (break into smaller sections), and more opportunities to connect with other participating teams.

All three teams intend to continue their efforts after the end of the pilot program, with implementation of many activities planned for later this fall or early 2010. Two teams indicated they feel the project has been beneficial in improving working relationships in their community, which aligns with the goal of building community capacity with this effort. The third agency has struggled to engage organizations beyond their own health system, but has indicated it has helped strengthen relationships between care settings within their system (hospital, home care, LTC, clinic).

The teams continued to identify finances/funding as a primary barrier. Other challenges cited include time, physician engagement, and challenges with collaboration between independent agencies.

When teams were asked what resources, other than funding, would be helpful, most indicated additional training/education and advice. Sharing of best practices was also cited as a helpful resource for continuation of efforts.

Recommendations/Lessons Learned

All three of the community teams participating in the NRHA Rural Palliative Care Pilot Project made progress beyond what was anticipated in the short timeline of this effort. Not only did each community form a team and identify an area of focus for action plan development, but each community made significant steps toward implementation of their action plans with intentions for sustained effort to continue to build on their progress thus far.

The findings of this pilot project reaffirm the belief that rural communities are uniquely positioned to meet the challenges of providing palliative care through collaborative efforts. A set process and timeline, access to palliative care program development expertise, and external facilitation to help initiate and develop community-based teams are important aspects that can assist in further development of community based palliative care efforts in rural areas.

Based on the pilot project results and experience, Stratis Health recommends expanding the pilot to reach additional rural communities, with the following adaptations to the program based on the pilot:

- All three teams identified the on-site community workshop as a key factor in their implementation of the pilot project. Future efforts should include this type of on-site community workshop to help ensure broad local participation and support. The locally based workshops also assisted in allowing for some physician participation, which can be even more challenging if travel to a session out of the area is required.

- Build connections with state organizations (such as the state hospice association or Flex Program), to foster sustainability and ongoing support for community-based palliative care efforts for participating rural teams.
- Structure opportunities for rural communities with similar areas of focus to connect and share tools and lessons learned in implementation.
- Although each team accomplished a great deal, the six-month timeline from recruitment to completion of this pilot project made it difficult for ongoing support and/or community sharing as teams implement their action plans. An extended timeframe such as one-year may allow for teams to be farther along in implementation of their action plans before the end of the formal project.
- Financial support for ongoing efforts related to palliative care services was identified by all the teams as an ongoing challenge. The lack of reimbursement for interdisciplinary palliative care services will continue to be a concern and barrier for the communities to fully implement team based palliative care. Policy changes for reimbursement of palliative care services, and/or grant funding to help sustain collaborative efforts would be extremely valuable in expanding rural palliative care services through this community-based model.



List of Appendices

- Appendix A: Advisory Group Roster
- Appendix B: Project Timeline

Appendix A: Advisory Group Roster

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Appendix B: Project Timeline

NRHA Rural Palliative Care Pilot Project Timeline

Project Implementation Overview:

Date	Activity
March, 2009	Community applications distributed by TA Advisory Group
April 17, 2009	Community applications due
April 30, 2009	Communities notified of participation
Early May, 2009	Community team completes needs assessment survey
Late May, 2009	Initial technical assistance call with Stratis Health
June, 2009	Community team meeting to discuss needs assessments and priorities
Mid/late July, 2009	Day-long visioning and planning workshop with community team
August, 2009	Technical assistance calls with Stratis Health
September, 2009	Joint conference call with all participating community teams to share strategies, lessons learned, and challenges (9/28). Complete evaluation of participation in pilot project. Final report due September 29.
Ongoing throughout project	Access to Stratis Health staff for consultation and identification of resources