The Challenge and Strength of Rural Hospice: Results from a National Study

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Alerus Convention Center
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Center for Rural Health

- Established in 1980, at The University of North Dakota (UND) School of Medicine and Health Sciences in Grand Forks, ND
- One of the country’s most experienced state rural health offices
- UND Center of Excellence in Research, Scholarship, and Creative Activity
- Home to seven national programs
- Recipient of the UND Award for Departmental Excellence in Research

Focus on
- Educating and Informing
- Policy
- Research and Evaluation
- Working with Communities
- American Indians
- Health Workforce
- Hospitals and Facilities

ruralhealth.und.edu

Rural Health Reform Policy RESEARCH CENTER

RHRPRC measures and projects the impact of health reform policies on rural and frontier communities.

- Interviews of Hospice CEOs
- Hospice access/utilization
- Rural emergency department use
- Impact of care coordination on the frontier Medicare beneficiaries’ quality and cost of care (FCHIP)
- Survey of hospice workforce
- Perspective of hospice beneficiaries’ family members
- Rural health chartbook
- End-of-life study
- RUCA 3 development
- FAR definitions
Research Supports Policy

- National Advisory Committee on Rural Health and Human Services – Advises Secretary of U.S. Department of Health and Human Services
  - Policy Brief: Rural Implications of Changes to the Medicare Hospice Benefit (August 2013)
  - Office of Rural Health Policy – funding of rural health research centers
  - New research center: Rural Health Reform Policy Research Center- focus on hospice and other issues
- National Hospice and Palliative Care Organization (NHPCO) Rural Task Force - instrumental in guidance and information – conf. calls.
- Kentucky Hospice Association Focus Group – June 2013

The Beginnings of our Research

- Determined there is a need and an interest
- Literature reviewed – extensive background
  - Rural Hospice in the United States An Annotated Review of the Literature
    [http://www.ruralhealthresearch.org/centers/rhrpc/](http://www.ruralhealthresearch.org/centers/rhrpc/)
- Conferred with experts – Rural Hospice Task Force and other individuals
- Kentucky Focus Group
- Task Force and overall association identified at least 1 rural hospice per state
- Methodology – mixed methods with quantitative and qualitative/primary and secondary sources
- Interviews with 53 Rural Hospice Directors, CEO’s, program officials (47 states)
- Literature and consultations with the association determined 6 primary focus areas for the interviews
Primary Focus Areas

- **Finance** – funding, reimbursement levels, payment process, finance policy
- **Regulations** – highly regulated sector, role and impact of rules and regs
- **Workforce** – demand/supply, shortages, issues impacting providers/staff
- **Relationship with other providers** – rural/urban hospice, for-profit/non-profit, hospitals, nursing homes, home health, competition/collaboration
- **Rural Factors** – common rural conditions that impact all or most rural health organizations (e.g., demographics, economics, distance/travel, culture)
- **Technology** – Advent and use of EMR, connectivity, adaptability, technology in the home
- **Strengths of Rural Hospice** – Many issues but what makes rural hospice special, if faced with so many problems what attracts people to work in rural hospice?
- **Future** – How do rural hospice leaders see rural hospice in 10 or so years?

* Ranking of Focus Areas

- **Finance** 15 respondents said number 1 concern
- **Rural Factors** 15
- **Regulations** 11
- **Workforce** 9
- **Relationships with others** 3
- **Technology** 0
Finance

Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Count</th>
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<tbody>
<tr>
<td>U-Shaped Curve</td>
<td>27 (hospice programs commented)</td>
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<tr>
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<tr>
<td>Sequestration</td>
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<td>Income/Economics (Area)</td>
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<td>Rural Hospice Culture</td>
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<td>Overall/Miscellaneous</td>
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Finance: U Shaped Curve

- Majority of those who commented favored it but there was skepticism and concern.
- Those who favored believed it would or could work in rural and is associated with a short length of stay.
- Generally those interviewed liked the concept and believed their costs are higher in the beginning of the patient care (due to intensity of care, set up, medications, equipment, and staff time) and in the final stages of care; however, during the middle the level of care is generally lower. Thus, the concept is applicable.
- Correspondingly the dominant concern was a strong feeling that they do not know the details. What will be the payment amount associated with the three phases? Are the phases measured in specific days for each phase, some patients a short time but others a very long time? Is it a percentage of days such as 1/3, 1/3, and 1/3 – how is it measured?
Finance: Reimbursement/Payment

- Comments that are more global and comprehensive in nature, and tend to express broader and generalized observations and concerns.
- A primary concern is how the current hospice reimbursement system treats rural hospices. There is a strong perception that the per diem payment (which is lower for rural hospices relative to an urban hospice) is inadequate.
- Rural hospice program officials tend to believe that they have cost structures that are different than found in urban and as such the per diem payment -- when combined with cuts in the market basket update and now the sequestration cuts -- does not cover their real costs.
- For example, reference was commonly made to the impact of travel costs, lost productivity, non-competitive salaries, and also medication and equipment costs that are also compounded by a low census and geographical distances. Thus, the perception exists that rural hospice is expected -- and should be expected -- to provide the same level and quality of services; however, the current reimbursement structure creates a service impediment for rural hospice agencies.

Finance: Travel/Distance

- Travel/Distance refers to the issue of “windshield time” on the road going out to see patients generally over a significant distance.
- For rural hospices this is a financial issue as they generally believe their per diem does not account for this “lost productivity time” or limits direct care time. Specific Concerns:
  - Paying mileage is an extra cost not adequately covered under a per diem.
  - Paying a salary for nurse or other staff to travel; lost productivity.
  - Rising gas prices.
  - Call schedules are hard to manage when staff covers great distances.
  - Many medical directors have full time individual practice and are with hospice on a part time basis so travel distances take them out of their office and impacts salary and physician productivity for non-hospice clinic.
  - Can have 100-200 hours a month in travel which is equivalent to another staff person.
  - Some see multiple thousands of miles in a single week.
Rural Factors

Themes

<table>
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<th>Factor</th>
<th>Percentage</th>
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<td>Travel/Distance/Geography</td>
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<td>Culture</td>
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<td>Population/Economics</td>
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<tr>
<td>Organization/Policy</td>
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<td>Workforce</td>
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- Rural factors are conditions in the overall rural environment that present unique challenges to rural hospice organizations.
- Rural factors could include a changing population (e.g., declining or growing population base, aging communities, less educated and qualified work force, smaller work force);
- economic conditions (e.g., poverty, lower income area, salaries not competitive, loss of jobs, declining economy);
- geography (e.g., distance, travel time, weather, physical barriers);
- rural culture (e.g., attitudes about hospice, sense of community, strong community relations, work ethic, pride, and how people relate to each other); and
- organizational structure and culture of rural hospice.

Rural Factors: Travel/Distance/Geography

- Very large service areas
- Remoteness and isolation – on your own, safety, limited resources/support, limited internet
- Increased costs due to travel expense, lost productivity, staff burnout, fatigue

Specific Concerns

- Large service areas where nurses, social workers, CNA, physicians have to travel to see a patient – (e.g., travel 50 miles one way; travel 75 miles one way; 90 miles one way; 100 miles one way; 120 miles one way; 10,000 square mile service area; 16,000 square mile service area; 18,000 square mile service area; 19,000 square mile service area; 20,000 square mile service area; 22,000 square mile service area; 1.5 hours or 2 hours one way to a patient; 19 county service area; 1.6 people per square mile)
- Can spend two or more hours on the road to see one patient, maybe see one or two a day.
- Distance impacts payment and need to stay, if can, within the per diem.
- Long time behind the windshield.
- Limited snow plow service and on the road.
- No public transportation, families are isolated.
- State rule is travel one hour out but we have to go 1.5 hours to a patient.
Rural Factors: Culture

• Culture is a very significant rural factor that influences the hospice experience.
• Hospice providers in rural areas need to be aware of how families and patients feel about privacy, openness to strangers in their home, independence, attitudes toward death, openness to sharing feelings and emotions, coping, and other natural reactions.
• Changing composition of rural population—limited diversity but other areas growing diversity of ethnic and racial groups, attitudes about death, privacy, take care of our own, outsiders
• Strong sense of community – helpfulness, caring for neighbors, staff seen as neighbors
• Rural traits – independence, privacy, stoicism, self reliance, but neighborly
• Limited awareness of hospice and how it can help, some physicians resist hospice

Specific Concerns

• Growing minority population presents challenges related to language; attitudes toward self-reliance, role of the family, death, and aging; and views toward medicine and medical providers that are different or slightly different than the dominant culture – issue of staff being bilingual or hiring interpreters.
• Religious view-points such as the use of medications, traditional medicine vs. herbal remedies.
• Illegal drug use can entail drug use by the patient and/or his/her family member – work closely with local law enforcement – safety issue for staff – family members have stolen patient’s medications.

Regulations

<table>
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<td>Staffing</td>
<td>24 (hospice programs commented)</td>
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<td>Face to Face</td>
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<td>General Regulatory Environment</td>
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<td>Regulation and Finance</td>
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<td>Other Regulations (not F2F)</td>
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<td>Impact on Quality</td>
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<tr>
<td>State Regulation</td>
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<tr>
<td>General Awareness of Regulations/Staying Updated</td>
<td>5</td>
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<tr>
<td>Organizational Structure</td>
<td>4</td>
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<tr>
<td>Hospice Policy</td>
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<tr>
<td>Discharge of Patients</td>
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Regulations - Staffing

- Overall, hospice program officials experienced an increased workload due to the number of rules and the pace of issuance of new rules and/or rule changes.
- There was a strong view that rule making is important as its primary purpose is to address quality, safety, and fraud; however, it also adds to the cost structure of rural hospice in the form of:
  - hiring additional staff (particularly administrative and some believed at the expense of improving care giving),
  - overburdening current staff,
  - equipment purchases in the form of more computers and software,
  - and while regulations have increased there was a corresponding decrease in reimbursement.
- In general, program officials believed that the regulatory environment placed an unfair burden on rural hospices as there is no real way to cover the additional costs associated with regulation within the current reimbursement system.

Regulations: Face to Face

- ACA requirement of a face-to-face meeting/assessment between a physician or nurse practitioner prior to a 180 day (6 month) recertification of the patient in hospice.
- The F2F is not billable as it is an administrative function performed by the physician or NP.
- The statute does not include hospices as a site for telehealth; thus, a telehealth encounter cannot be used as a substitute for a direct F2F.
- The use of a narrative dates back to 2009 when hospice physicians had to develop a narrative for all new patients and whenever patients were recertified.
- The face-to-face requirement is controversial for rural hospices. On one hand a number of hospice program officials feel it is important and necessary to have a reassessment of the patient in order to assure the appropriate use of the benefit and to serve as a quality of care process; however, they point to a number of inequities that place additional burden on their agency and staff.
- Rural hospice officials clearly identified F2F as a regulation that created staffing concerns increased costs, and had geographical constraints.
Regulations: Face to Face

• In general they see the situation as one where they have had to add staff in the form of nurse practitioners and even physicians when their overall census may not support this but in order to have medical staff that can conduct a F2F they have had to do so. This also creates time allocation issues.

• The staffing impacts costs, as do perceived lost productivity due to the need to travel great distance that take a provider away from providing more direct care services. Costs are also exacerbated in that the physician encounter is seen as an administrative function and is not billable. And, under current law, technology cannot be used in place of a F2F or as a tool to augment the encounter.

• There is some feeling that the F2F not only does not improve the overall quality of care provided but due to the fact that providers are engaged in an administrative function it actually detracts from direct patient care.

• Issues such as travel/distance, increased costs, and staff impacts were the most commonly identified issues.

Regulations: Overall Regulatory Environment

• Refers to perceptions that address the overall environment faced by rural hospices and correlates more with the perceived culture of regulation and its impact on rural hospices.

• Many of the comments raised concerns over the perceived increase in the number of regulations and the apparent rapid pace rural hospice feels they are being developed.

• Interviews produced a sense of being overwhelmed, not having enough staff to adequately deal with regulations, that costs are going up as a result, and that the level and intensity of the scrutiny has ratcheted-up.

• A couple of directors expressed concern that the environment is one where rural hospices feel defensive and essentially have to prove themselves to regulators.

• There was even a sentiment expressed by one hospice program official that the effect of this regulatory environment will hasten the demise of rural hospice to the benefit of urban, for-profits.
Workforce

Themes

• Workforce Environment
  o Supply and Demand: 34 comments
  o Workplace Environment: 17 comments
  o Competition: 15 comments
  o Workforce Economics: 14 comments
  o Rural Factors: 13 comments
  o Regulations: 10 comments

• Specific Workforce Disciplines
  o Nursing: 39 comments
  o Social Work: 30 comments
  o Physicians: 27 comments

51 hospice programs comments

40 hospice program comments

Workforce Environment: Supply and Demand

Specific Comments

• Supply is adequate - Workforce is solid and have long term employees.
• Finding qualified employees is hard, but getting better.
• Extremely low turnover as have an organizational commitment to be an employer of choice.
• Hard to recruit and retain qualified staff into a rural environment.
• Issue is the quality of the candidates, sometimes hire someone who lives 60 miles away and then they have to drive, but are the best candidate.
• Retention is important and invest in them and their needs, use staff surveys to learn what they need, high expense but worth it.
• Grateful for current staff but replacing them will be hard due to different expectations about work, dealing with the travel, the weather, new employees less likely to put up with these issues.
• New generation of workers is different, have different expectations and demands – don’t want to work night shift, don’t want to travel – really not oriented to the hospice culture about sacrifice.
• Hard to find people with the right level of experience, steep learning curve for hospice nurses, social workers, - hospice is a different type of health care.
Workforce Environment: Workplace, Rural Factors, Competition

Workplace – Specific Comments
• High workload, small staff, overworked staff, physicians have huge patient load.
• Training and overall CE is a problem, try to use as much on-line as possible but have connectivity issues, training in person at a conference is costly as it is 175 miles away.
• Newer workers get burned-out by hospice faster due to the travel and being on-call.

Rural Factors – Specific Comments
• Proximity to urban – workforce has a number of employment choices.
• Some do not understand the amount of travel, bad roads, mountainous travel.
• Loss of population leads to smaller, qualified candidate pools.

Competition – Specific Comments
• More competition with long term care, nursing homes and assisted living.
• Compete with for-profits that have moved into the area, competition can be good, but these for-profits have great sums of money for marketing/advertising.
• Lot more competition in the community, our reimbursement as a rural hospice is lower so harder to compete with urban for-profit hospices for staff, especially nurses.

Strengths of Rural Hospice

- Hospice Culture
  33 hospice programs commented
  Staff/employees
  20 hospice comments
  Helping/caring/nature of hospice
  19
  Type/level/quality of care
  12
  Trust
  11

- Community Support
  19 hospice programs commented

- Rural Culture
  17 hospice programs commented.
Strengths: Hospice Culture – staff, caring nature, level of care

Staff – Specific Comments
• Rural hospice have staff caring for people they grew up with and know (Numerous comments)
• They feel more comfortable with nurses who lived here all their lives.
• Relate to the people we care for and they with us when we have grown up together.
• My nurses provide care in the community where they live and where they grew up.

Caring Nature – Specific Comments
• Real sense of people taking care of their own.
• Familiarity and compassion is more genuine than in an urban area.
• Commitment to put the patient first, here to serve the patient.

Level/Type/Quality of Care – Specific Comments
• Provide the level of care as if they were your family.
• We take the linens and wash them for patient, large hospices are not able to do this.
• Ability to bring this specialized care to people in rural areas who might not otherwise receive it.

What Does the Future Look Like for Rural Hospice?

Themes
• Organizational/Policy Change 28 hospice programs commented
• Loss/Decline 20
• Community Support 3
• Rural Culture 3
• Medical and other Staff 2

• Organizational/Policy Change - how it is organized, relationships with other organizations, changing structures, service needs, efficiency, and broad health policy implications related to regulation and payment.

• Loss/Decline - general sense of anticipated negative change and the system and environment for rural hospice will decline. This is expressed through views that rural hospice will be different in the future and that difference will represent and reflect a loss in what exists today.
Future: Organizational and/or Policy Change

Specific Comments

• More consolidation, mergers, and coordination (with hospitals, nursing homes, urban systems, urban for-profit hospices).
• More urban take-over of rural hospices, more for-profit take-overs.
• See a decline in the number of rural hospices, particularly the small, independent non-profit.
• Increased palliative care options.
• Recognize that while the regulations are the same for all hospices, costs vary and so does reimbursement.
• Continued access issues.
• More opportunities for public education importance of hospice, and more awareness.
• Growing importance of federal policy and more regulation.
• Larger system may be able to expand the number of services and operate more economically but could happen at the expense of the culture found in rural hospice.
• Need for leadership and vision.
• Expansion of services beyond traditional hospice to gain efficiencies of scale, expand service area, more branch sites, more technology.
• Will need to increase efficiency.
• Health policy change such as the ACA may foster new arrangements that bring in more efficiency.

Future: Sense of Loss and Decline

Specific Comments

• Rural hospice as it operates today will cease to exist.
• Less access to hospice services in rural areas.
• Decline in number of independent, non-profit.
• Continued and new workforce challenges – hard to find workers, continued population declines lessens workforce supply.
• Growing elderly population but declining resources to care for them.
• Uniform treatment of rural and urban hospices will be detrimental to rural hospice.
• Slow, continued decline if public is not educated on hospice care.
• Increased cost of care.
• Growing uncertainty.
• Growing awareness and acceptance of hospice.
• Lack of awareness and acceptance of hospice.
• Fewer services.
• Regulations and reimbursement barriers to rural hospice.
Conclusions

- Sincere dedication to patients and family – commitment and values
- Strong sense of community and understanding of the nature or rural culture
- Perception that rural hospice is different than urban or at rural independent non-profits different than urban for-profits in motives, values, structure, resources, and financing.
- Fragile hospice system – heavily regulated, inadequately financed, and growing workforce problems.
- Importance of rural factors e.g., travel and distance, culture, population.
- General pessimism – sense of loss and decline, losing to the big guys, loss of a way of life and a type of personalized care.
- Need for strong policy advocacy and policy change.

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