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Quality of Hospice Care: Comparison between Rural and Urban Residents

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Abstract

Discrepancies between needed and received hospice care exist especially in rural areas. Hospice care quality ratings for 743 rural and urban patients and families were compared. Rural participants reported higher overall satisfaction and with pain/symptom management. Regardless of geographic location, satisfaction was higher when patients were informed and emotionally supported. Patients and family ratings did not differ. Findings support prior reports using retrospective rather than our study's point-of care surveys.

Keywords

family; hospice care; patient satisfaction; quality care; rural health

In 2011, 1.65 million people in the United States (US) received hospice care, and 44.6% of patients were under the care of a hospice provider at time of death; still more than 1 million people each year who could have benefitted from hospice care die without receiving it.¹ Hospice care is underutilized despite availability of more than 5300 hospice programs in a variety of settings: freestanding (57.5%), part of hospital systems (20.3%), home health agencies (16.8%), or nursing homes (5.2%).² Patients in rural communities are especially vulnerable to receiving inadequate hospice care. A multitude of factors can explain the discrepancy between needed and received hospice care in rural communities including less

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hospice provider access, challenges delivering hospice care, characteristics of the rural populations, and beliefs about hospice care and the quality of such care.³⁻⁹

Rural communities have less access to hospice care programs.³ In 2008, 98% of US residents lived within 60 minutes driving time to at least one hospice.¹⁰ However, for states with a high proportion of rural residents, for example North Dakota and South Dakota, more than 10% of their population lived further than 60 minutes driving time from a hospice. Moreover, driving time does not equate service area or access to hospice. Some hospice programs have a limited catchment area that may not include rural areas. Further rural counties are less likely to have at least 1 Medicare-certified hospice program when compared to urban counties.⁴

Challenges delivering hospice care for rural programs include geography, resources, and staff education and retention. Geographical challenges in rural areas consist of unpredictable access to patient homes due to weather, topographical features, poorly maintained roads, and long distances between homes.⁵ Resource challenges include financial constraints. With fewer financial resources, fuel costs impact frequency of visits. Further, there may be fewer resources such as medications and equipment in local pharmacies and health supply stores.^{5,6} Finally, lack of education for staff about hospice care and low retention of hospice staff create serious challenges to delivering hospice care in rural communities.^{6,7}

Characteristics of the rural populations are also reasons for discrepancy between needed and received hospice care. Compared to their urban counterparts, rural communities may have higher needs for hospice care as they have higher proportions of people who are older than 65 years of age with multiple comorbidities.⁴ Further rural residents are poorer and therefore may not seek care because of cost. With 22.7% of the rural population living on government transfer payments compared to 13.7% in urban areas, more rural patients and families struggle to pay for medications, equipment, and supplies.^{5,7}

Finally, patient and family beliefs about hospice care can contribute to underutilization of hospice care in rural communities.¹¹ Rural residents may not be aware that hospice care is available. Because scarcity of medical resources is often the norm in rural communities, it may not occur to patients and families to explore if hospice care is offered.⁹ Further, patients and their families may equate hospice care with death and therefore not seek hospice care until very late in the dying process.⁹ Finally, patients and families may be reluctant to seek hospice care if they perceive their hospice provider does not deliver quality care. Low levels of coordination and communication among hospice providers, and less standardized assessment tools, care plans, and charting mechanisms have been reported in rural communities.¹¹

The national focus on quality of hospice care has increased since 2008 when the Centers for Medicare and Medicaid (CMS) included hospice care in their initiatives to improve health care quality. To receive reimbursement from CMS, hospice programs are required to have quality assessment and performance improvement initiatives.¹² Further, the National Quality Forum (NQF) has endorsed 14 quality indicators for hospice care.¹ These quality indicators address care outcomes, such as communication about patients' condition, plan of care,

symptom management, and psychosocial support, but the indicators do not include outcome measures that evaluate actual results of care.^{13–15} In contrast the National Hospice and Palliative Care Organization's (NHPCO) Family Evaluation of Hospice Care survey (FEHC) examines families' satisfaction with hospice care. The FEHC is part of the NHPCO's national performance improvement program whereby hospices that submit data to NHPCO receive quarterly benchmark reports with state and national comparisons.¹⁶ The FEHC does not include patients' opinions, however, as the survey is distributed postmortem. A few studies have compared family and patient ratings of satisfaction with mixed results.^{17,18} To our knowledge there are no studies that compare quality of hospice care in rural and urban areas and include data collected from both patients and families. The aim of the present study was to examine whether perceptions of quality of hospice care differed in rural and urban areas and between patients and families.

METHODS

The study is guided by the Quality Health Outcomes Model (QHOM). The QHOM is based on Donabedian's model of structure, process, and outcomes, which has provided a framework for the evaluation and comparison of health care quality since the 1960s.^{19,20} The QHOM depicts the interrelationships between the system, interventions, patient characteristics, and outcomes. The QHOM was adapted for the current study to evaluate hospice care quality. Consistent with mandates to link hospice interventions with patient/family outcomes,¹² the QHOM depicts how hospice interventions affect hospice outcomes through system or patient characteristics. We conceptualize the system characteristics as geographic and care location; the hospice interventions are whether the following care was provided: explanation of plan of care, information about patient's condition, and emotional support; patient characteristics include race/ethnicity, primary diagnosis, and relationship to patient; and hospice outcomes are overall satisfaction, satisfaction with pain management, and satisfaction with other symptom management. Using both patient and family respondents, this study assessed what specific hospice interventions are associated with what hospice outcomes in rural and urban areas.

Data sources and study population

We used a convenience sample of patients admitted to 1 large hospice program in the Southeastern US from September 1, 2009 through April 30, 2010. The hospice organization's service area was divided into 7 areas where each had a home visit team and an inpatient facility. The organization had an average daily census of 630 patient/families with about 25% of their population in rural areas. As part of their quality assessment, the hospice organization had the same staff person do a 5–10 minute survey of all patients and/or adult family/significant other 4–10 days after admission. For this study the survey was modified to include patients' zip code and satisfaction questions for care interventions related to pain management and other symptom management for a total of 13-questions. For the 8-month study period, the research team received monthly deidentified patient level data.

Measures

System characteristics were measured as geographic and care location. These variables were extracted from admission forms. Geographic location was defined as rural or urban. From the patient's residential zip code we extracted the county codes from the Center for Disease Control.²¹ We then merged the county codes with the Economic Research Service's rural/urban continuum codes to determine rural or urban location.²² Codes 1–3 were designated urban and codes 4–9 rural. Care location was either at home or at an inpatient hospice unit. *Patient characteristics* had 3 variables. Race/ethnicity was white, African-American, or other. Primary diagnosis was cancer or non-cancer. Both were extracted from the admission form. The individual who answered the survey questions described their relationship to the patient as self, spouse, adult child, or other.

Hospice interventions included 3 binary variables: explanation of plan of care, information about patient's condition, and emotional support which were all measured as whether an intervention had been provided or not. *Hospice outcomes* included 3 binary variables: overall satisfaction, satisfaction with pain management, and satisfaction with other symptom management. All 3 variables measured whether the person who answered was satisfied with the hospice care or not.

Data analysis

Descriptive summaries were created using percentages and frequencies and then compared according to geographic location using Chi-square test. For cell sizes less than 5 Fisher's exact test was employed. We used logistic regressions to first examine univariate associations between variables and each hospice outcome and then multivariate associations including all significant variables. Since our aim included geographic location and relationship to patient these 2 variables were included in all multivariate models. Due to collinearity between the 3 hospice interventions we included them 1 at a time for 3 separate models. All analyses were done using SPSS version 18.0 (IBM Corp. Armonk, NY).

RESULTS

A total of 743 (331 rural and 412 urban) surveys were included in the study. During the study period 2073 patients were admitted to the hospice but 621 died before they could be surveyed, 617 patients could not be reached or did not want to participate, and 92 surveys were either duplicates (n=24), or had missing data (n=68). In both rural and urban areas, 67% of admitted patients received hospice care at home (Supplemental Digital Content, Table). Compared to patients in urban areas, rural patients were significantly more likely to be white (90%) and less likely to be African American (7.9%). For both rural and urban areas slightly more than half of the patients had a non-cancer diagnosis and the respondent was least likely to be the patient (16.3%) and most likely to be an adult child followed by spouse and other. The 3 hospice interventions had been provided 89.8% to 94.9% of the times with information about patient's condition scoring lowest in urban areas and emotional support scoring highest in rural areas. Overall satisfaction, satisfaction with pain management, and satisfaction with other symptom management were rated positive in 93.2% to 99.4% of the times. For overall satisfaction, there were only 3 patients in rural

areas who were not satisfied so Fisher's exact test was used and produced a significant difference.

Since overall satisfaction only had 3 rural patients that were not satisfied, we did not include logistic regressions results. In the univariate analyses satisfaction with pain management was associated with only the 2 interventions: information about patient's condition and emotional support, while satisfaction with other symptom management was associated with all three hospice interventions. Care location, race/ethnicity, primary diagnosis, and relationship to patient were not associated with any of the hospice outcomes.

In the final multivariate logistic regression models (Table), the 2 hospice outcomes were consistently more likely to be rated higher if 1 of the 3 hospice interventions were in place. For the outcome satisfaction with pain management, only the intervention explanation of plan of care was not significant; whether patient or others were surveyed was not significant. For the 2 hospice outcomes, rural location was approaching significance (pain management odds ratio 1.54, $p=0.19$; symptom management odds ratio 1.97, $p=0.06$). While the outcome overall satisfaction did not meet the assumption of more than 5 cases per cell, when we did logistic regression, all 3 care interventions were significant as was rural location.

DISCUSSION

Satisfaction with hospice care was high in both rural and urban areas. This finding is consistent with high satisfaction ratings of hospice and palliative care services found in the literature.^{23–25} In this study rural patients and families rated their overall satisfaction so high that we were unable to do robust logistic regressions. So the lack of resources often found in rural areas, were either not present or did not influence patient and family satisfaction with hospice care in this study.^{5,26} Perhaps the high ratings can be contributed to the rural communities' connectedness.^{26,27} Hospice providers can more quickly get the services their patients need because they have a personal relationship with the other providers within the community.⁸ Rural nurses plan highly individualized care, and they go beyond their allotted hours to ensure patients receive best care.⁸ Finally, in rural communities neighbors tend to be conscious of each other's needs and help out if necessary.⁸

Satisfaction with hospice care did not differ between patients cared for in their home or in an inpatient hospice unit. In this study patients were served by a large hospice, which has been operating in both rural and urban areas for many years. The rural communities know their hospice providers and the hospice is recognized for providing high quality care. For many rural areas this type of provider is not available. Although both hospice utilization and number of providers have increased from 2000–2009, the increase in providers were the highest in urban areas (62% increase and 31% respectively).²⁸ Therefore many rural patients may be sent out of their community to an urban area when their care needs demand inpatient admission.²⁶ Not being around people they know may result in lower inpatient satisfaction.

The high satisfaction ratings with pain and other symptom management suggest the hospice providers were able to treat symptoms quickly after admission to hospice. With at least 1 visit, the hospice care team was able to address symptoms satisfactorily for more than 90%

of the patients. Our ratings are better than previously reported satisfaction with symptoms management reduction between 2 visits. For pain management a reduction from moderate/severe to mild/none was reported by 56% of patients, and for other symptoms management (dyspnea, depression, and constipation), a reduction was reported by 54%–65% of patients.²⁹

All 3 interventions, explanation of plan of care, information about patient's condition, and emotional support were associated with higher ratings of satisfaction from patients and families. This confirms other findings using the FEHC where family members rated overall satisfaction higher if they were informed about the patient's medical treatment, were provided regular information about the patient's condition, and felt the hospice team provided emotional support.³⁰

In our study there were no significant difference between patient and family satisfaction. Other studies have also found that patients and families view of hospice care quality was similarly.³¹ In contrast a previous study found that patients were less likely to be satisfied with overall hospice care compared to all other respondents.¹⁸ One should note as in any survey there is a potential bias because the patient population only represents patients willing and able to participate in the survey. Patients' ability to participate may be impaired as they go through the dying process.^{30,31} Nonetheless both patients and families perceptions should be included when planning hospice care and measuring quality.

Race/ethnicity did not influence satisfaction in this study. In a retrospective study African-American families were less satisfied than white families.²⁴ Numbers of patients and families within each race/ethnicity category, however, is different in our study. Our sample had both more white (85.2 %) and African-American (11.6%) patients compared to the 2010 national averages of 77.3% and 8.9% respectively.² Perhaps the aforementioned longevity of the hospice provider also has a positive effect on possible disparities related to race/ethnicity. Just as might be the case in the rural communities, this hospice provider is a known entity in the African-American community and therefore used and trusted to provide quality care.

Limitations

Our study had several limitations. We used a convenience sample of hospice patients and families with a higher proportion of rural patients (45%) compared to the 25% that are rural in the population the hospice serves. Our results therefore may not reflect the perceptions of the population served. Further, more than half of the patients admitted to this hospice and therefore eligible to be in the study died, could not be reached or declined participation. The large proportion of patients who died before they were reached indicates that our population pursued hospice care late in the dying process which unfortunately is not unusual. Also, it should be noted that we had less variability in this sample of 743 patients and families than expected. Only 4–9% of participants had not received hospice interventions or were dissatisfied with the hospice outcome. Therefore we were unable to report robust results from one outcome: overall satisfaction with hospice care, and some of our confidence intervals are large. Nevertheless, our statistically significant findings are valid as they are

based on the 95% confidence intervals that do not cross 1 ($p < .05$). Future studies with larger sample sizes are needed to confirm these results.

Another limitation relates to generalizability. The hospice program in this study had an average census of 630 patients/day. In contrast the median average daily census in 2011 was 71.² Further with 1/4 of their population in rural areas this hospice is also a large provider in rural communities. Studies including a variety of hospice providers in both rural and urban areas are warranted to validate or dispute our results. Finally, our study only considered geographic and care location as contextual factors. Other contextual factors and their relationships to interventions and outcomes are important to consider when examining quality.³²

CONCLUSION

Our results have implications for practice, policy, and research. In order to provide high quality care hospice providers need to assure they use all three interventions: explanation of plan of care, information about patient's condition, and emotional support. These interventions are not unique to hospice care, but especially important with end-of-life care where patients and families have to come to terms with the approaching death of a loved one. In rural communities, hospice providers also need to pay attention to and include the informal networks surrounding the patient and families. At the policy level our results demonstrate potential for support of integration of measures from point-of-care systems collection methods that can help guide ongoing quality monitoring. Together with retrospective surveys meaningful benchmark reports on interventions and hospice outcomes can be produced for regulatory and payment purposes. Future research should include other hospice interventions and outcome as well as what aspects of living in a rural area may explain the higher satisfaction with hospice care found in this study. Finally researchers should include open-ended questions for addressing problems as they occur and for further qualitative analyses, which will aid in development of patient and family centered interventions and measurements to ensure hospice quality care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table

Multivariate logistic regression for hospice outcomes (N=743)

	Satisfaction with pain management	Satisfaction with other symptom management
	Odds ratio (95% CI)	Odds ratio (95% CI)
<u>System Characteristics</u>		
Geographic location		
<i>Rural vs urban</i>	1.54 (0.81–2.93), p= .19	1.97 (0.98–3.95), p= .06
<u>Patient Characteristics</u>		
Relationship to Patient		
<i>Self vs all others</i>	1.21 (0.5–2.94), p= .67	0.76 (0.34–1.7), p= .51
<u>Hospice intervention</u>		
Explanation of plan of care	1.67 (0.57–4.9), p= .35	3.08 (1.21–7.83), p = .018
Information about patient's condition	6.08 (2.99–12.33), p< .001	7.12 (3.45–14.73), p< .001
Emotional support	3.73 (1.62–8.62), p< .001	5.94 (2.68–13.2), p< .001

Hospice interventions were included 1 at a time in all models. Results for geographic location and relationship to patient are from the model that included these 2 variables and the hospice intervention explanation of plan of care.