

Barriers to Quality Care for Dying Patients in Rural Communities

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ABSTRACT: *Context:* Barriers to providing optimal palliative care in rural communities are not well understood. *Purpose:* To identify health care personnel's perceptions of the care provided to dying patients in rural Kansas and Colorado and to identify barriers to providing optimal care. *Methods:* An anonymous self-administered survey was sent to health care personnel throughout 2 rural practice-based research networks. Targeted personnel included clinicians, nurses, medical assistants, chaplains, social workers, administrators, and ancillary staff, who worked at hospice organizations, hospitals, ambulatory clinics, public health agencies, home health agencies, and nursing homes. *Findings:* Results from 363 completed surveys indicated that most health care personnel were satisfied with the palliative care being provided in their health care facilities (84%) and that most were comfortable helping dying patients transition from a curative to a palliative focus of care (87%). Yet, many reported that the palliative care provided could be improved and many reported that family members' avoidance of issues around dying (60%) was a barrier to providing optimal care in rural health care facilities. *Conclusions:* Findings suggest that health care personnel perceive they are effective at providing palliative care in their rural health care facilities, yet face barriers to providing optimal end-of-life care. Results of this study suggest that differences in training and experience may influence health care personnel's perceptions of the existing barriers. It may be important in rural areas to customize interventions to both the professional role and the site of care.

Over the past few years, there has been a growing level of commitment to improving the care of dying patients.¹⁻⁵ However, the differentiation between life-prolonging treatment and palliative care remains controversial,⁶ problematic, and unclear.⁷ Providing optimal care for people near their end of life remains a major challenge facing health care professionals today.⁸

Palliative care is the active total care of the body, mind, and spirit.⁹ Optimal end-of-life care often consists of transitioning care from a curative to a palliative focus, alleviating suffering and improving the quality of living and dying.^{10,11} Yet, major barriers to the delivery of optimal palliative care have been well documented in the literature.^{4,12-19} Few studies, however, have focused on the perceptions of health care personnel in rural communities in the United States²⁰ where unique challenges to receiving and delivering palliative care services may exist.¹⁶

The purpose of this study was to describe health care personnel's perceptions of the care provided to dying patients in rural Kansas and Colorado and to identify potential approaches to improving end-of-life care in rural health care facilities.

Methods

Setting and Subjects. The study setting was 2 rural practice-based research networks: the High Plains Research Network in northeast Colorado and the Kansas Practice Research Network.

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A convenience sample of health care personnel, including physicians, physician assistants, nurse practitioners, nurses, medical assistants, social workers, chaplains, administrators, and ancillary staff at hospitals, ambulatory clinics, nursing homes, hospice organizations, home health agencies, and public health offices, were invited to participate.

Study Design. We used an anonymous self-administered survey. Surveys were sent to key personnel in the health care facilities for distribution rather than directly to individual staff. This was done because it was infeasible to obtain accurate personnel lists due to numerous factors unique to rural medical care, including the transient nature of some employees (eg, float nurses) and multiple work locations (eg, hospice workers covering entire counties, working in both nursing homes and clinics). Therefore, we were unable to calculate a response rate for this study. Institutional review board approval was obtained.

Survey. For the purpose of the survey, “palliative care” was defined as “comprehensive care for patients and families living with a life-threatening or terminal illness, particularly where care is focused on alleviating suffering and promoting quality of life.” The survey consisted of ordinal-scaled and open-ended questions regarding beliefs on the effectiveness of and satisfaction with end-of-life care and the difficulties in identifying dying patients. Respondents were also asked to choose from a list of 19 potential barriers to providing optimal care those that they believed existed in their facilities. The survey instrument had been previously pilot tested on design, content, and respondent burden and used in a previous study.²¹ For this study, minor modifications were made to the original survey, including the addition of questions to assess the potential use of a palliative care consult team and to determine the clinical care site of the respondent.

Analysis and Data Management. All analyses were conducted using SAS version 9.0 (SAS Institute, Inc., Cary, NC). The chi-square test and Fisher exact test were used to determine associations between respondent demographics and responses. Analysis of variance was used to examine differences between groups in the perceived frequency of specific barriers to appropriate care, which were rated on a 5-point scale (1 = never, 5 = always).

Our final analyses aggregated those respondents providing medical care into 3 categories: clinicians (physicians, physician assistants, and nurse practitioners), nurses (clinical nurses and nurse managers), and medical assistants. Because medical

assistants in rural communities often provide high levels of care to dying patients, we believed that it was important to obtain their perceptions to be able to plan effective education and support services for all the team players in the delivery of palliative care in the rural communities.

We asked the respondents to indicate the type of institution in which they provided care. We classified the type of facility into hospital, clinic, multiple sites, hospice only or in combination with another site, long-term care (LTC) facility, and other (eg, home health, health department). Because we expected that people who work within hospice organizations would have different training and experience in end-of-life care than those who do not work in hospice, we reclassified the respondent’s type of institution as “hospice” if the respondent indicated that he or she worked in hospice only or in any combination of hospice with another facility. Due to the small sample size in the “other” category and the difficulty in interpreting respondents’ answers who worked in multiple sites, we chose to eliminate these responses for site of care analyses.

Findings

Of the 363 surveys returned, 195 (54%) were from Colorado and 168 (46%) from Kansas. Table 1 describes the participants in this study.

Half of all the respondents reported that palliative care could be improved at their facility (50.3%, Yes; 36.4%, Maybe; 13.3%, No). Significantly, more nurses and clinicians than medical assistants reported that palliative care could be improved (91% nurses, 88% clinicians, 71% medical assistants; $P = <.001$).

Eighty-four percent of all respondents were “satisfied” or “very satisfied” that palliative care is provided, and 85% of all respondents were satisfied or very satisfied that patients are informed of different care options. Ninety-one percent of all respondents reported that advance directives are followed.

The majority of respondents indicated that their facility was very effective at providing 3 of 7 key components of end-of-life care (Table 2). However, more than half reported that their facility was either not at all or only somewhat effective at providing psychological support for dying patients, attending to spiritual needs, and providing grief support.

Thirty percent of all respondents believed that the transition from curative to palliative care was frequently or always made too late. Still 89% of all respondents agreed that they felt comfortable knowing what to do for the dying patient and 87% of respondents felt comfortable helping patients transition from curative to palliative care. A higher proportion of hospice and LTC

Table 1. Characteristics of Respondents*

Characteristic	All N = 363	Colorado N = 195	Kansas N = 168	P
	n (%)	n (%)	n (%)	
Age of respondent (in years)				NS
<25	22 (6.1)	12 (6.2)	10 (6.0)	
25–54	279 (76.9)	149 (76.4)	130 (77.4)	
>54	50 (13.8)	28 (14.4)	22 (13.1)	
Did not provide	12 (3.3)	6 (3.1)	6 (3.6)	
Sex				NS
Female	316 (87.1)	172 (88.2)	144 (85.7)	
Male	44 (12.1)	21 (10.8)	23 (13.7)	
Did not provide	3 (0.8)	2 (1.0)	1 (0.6)	
Race				NS
White, not of Hispanic origin	340 (93.7)	179 (91.8)	161 (95.8)	
Nonwhite	9 (2.5)	5 (2.6)	4 (2.4)	
Hispanic	6 (1.7)	5 (2.6)	1 (0.6)	
Did not provide	8 (2.2)	6 (3.1)	2 (1.2)	
Professional role				.02
Nurse	194 (53.4)	90 (46.4)	104 (61.9)	
Medical assistant	62 (17.1)	39 (20.0)	23 (13.7)	
Clinician	49 (13.5)	28 (14.4)	21 (12.5)	
Social worker	15 (4.1)	7 (3.6)	8 (4.8)	
Administrator	10 (2.8)	8 (4.1)	2 (1.2)	
Other	33 (9.1)	23 (11.8)	10 (6.0)	
Site of care				<.001
Hospital only	102 (28.1)	73 (37.4)	29 (17.3)	
LTC facility only	96 (26.5)	39 (20.0)	57 (33.9)	
Hospice†	75 (20.7)	21 (10.8)	54 (32.1)	
Multiple sites	61 (16.8)	39 (20.0)	22 (13.1)	
Ambulatory clinic only	18 (5.0)	18 (9.2)	0 (0)	
Other	11 (3.03)	5 (2.6)	6 (3.6)	

*NS = Not significant.

†Multiple sites of care could be selected. Hospice includes hospice only or any combination of hospice with another facility.

workers than hospital workers felt comfortable knowing what to do (96% Hospice, 94% LTC, 84% Hospital; $P = .02$) and helping patients make this transition (99% Hospice, 95% LTC, 82% Hospital; $P < .001$).

Overall, 76% of respondents reported that health care personnel do a good job identifying when a patient is dying, with higher rates of medical assistants (90% medical assistants, 75% nurses, 71% clinicians; $P = .02$) and hospital and LTC employees (87% Hospital and LTC, 59% Hospice; $P < .001$) indicating agreement.

The majority of respondents indicated that barriers to initiating palliative care included a concern about “giving up too soon” (82%), the problem of “knowing when to quit” (85%), difficulties communicating with family (82%), problems related to differences in training/experience among different personnel (74%), and feeling pressured by patient/family to continue treatment (87%). Nurses more often reported

difficulties communicating with family (on a 5-point scale [1 = never, 5 = always], mean ratings were 2.18 nurses, 2.0 clinicians, 1.75 medical assistants; $F = 8.72$, $P < .001$) and differences in training/experience (mean: 2.04 nurses, 1.77 clinicians, 1.73 medical assistants; $F = 4.73$, $P = .01$). Clinicians more frequently indicated giving up too soon (mean: 2.35 clinicians, 2.10 nurses, 1.95 medical assistants; $F = 3.79$, $P = .02$) and knowing when to quit influenced their decision to label a patient as dying (mean: 2.44 clinicians, 2.24 nurses, 1.84 medical assistants; $F = 10.4$, $P < .001$). Hospice workers more frequently reported being influenced by a concern about giving up too soon (mean: 2.47 hospice, 1.92 hospital, 1.96 LTC; $F = 13.94$, $P < .001$), the problem of knowing when to quit (mean: 2.51 hospice, 2.10 hospital, 1.96 LTC; $F = 12.22$, $P < .001$), and difficulties communicating with family (mean: 2.25 hospice, 2.14 hospital, 1.83 LTC; $F = 8.01$, $P < .001$).

Table 2. Proportion Reporting Their Facility as Very Effective in Different Areas of End-of-Life Care

	Pain Assessment	Pain Management	Other Symptom Management	Psychological Support for Dying Patients	Attention to Spiritual Needs	Grief/Bereavement Support	Coordination of the Care Plan
Respondents overall role	61.3	59.6	60.0	46.5	42.1	43.0	51.3
Medical assistant	58.3	50.9	62.7	45.8	50.0	48.3	59.3
Nurse	59.0	59.0	56.8	48.4	39.0	44.9	49.5
Clinician	64.6	66.7	62.5	47.7	50.0	40.4	51.1
Respondent site of care							
Hospital	67.3*	64.3*	59.2*	44.7*	38.1	38.5*	47.4
Hospice	73.3	73.3	74.7	65.3	52.8	61.6	62.7
LTC	53.3	51.6	57.6	44.7	41.3	45.7	61.4

* $P \leq .05$.

Table 3 describes the most frequently selected barriers (>30% of respondents) to providing palliative care. Only family members' avoidance of issues around dying was perceived as a barrier by half or more of all the respondents. Other commonly noted barriers included patients' avoidance of issues around dying and communication difficulties. A higher proportion of clinicians and nurses noted family members' avoidance of issues around dying as a perceived barrier, and a

higher proportion of clinicians reported patients' avoidance of issues around dying as a perceived barrier. More hospice and hospital workers noted family or patients' avoidance of issues around dying as perceived barriers compared to LTC workers, while LTC workers were more apt to say that personnel shortages/time constraints were barriers. Furthermore, hospice and LTC workers noted communication difficulties among health care personnel as a barrier.

Table 3. Most Frequently Reported Perceived Barriers to Providing Optimal End-of-Life Care

Barrier	All Respondents (N = 363)	Respondent Professional Role				Respondent Site of Care			
		Medical Assistants	Nurses	Clinicians	P	Hospitals	Hospice	LTC	P
Family members' avoidance of issues around dying (%)	60.3	41.9	64.4	67.4	.004	66.7	73.3	45.8	<.001
Differences in opinion among health care professionals (%)	48.8	48.4	51.6	42.9	.54	46.1	48.0	56.3	.33
Patients' avoidance of issues around dying (%)	47.1	32.3	49.5	61.2	.008	54.9	58.7	26.0	<.001
Communication difficulties among patients and their families (%)	39.9	27.4	44.3	42.9	.06	40.2	49.3	33.3	.11
Health care professionals' personal discomfort with death (%)	38.6	29.0	42.2	36.7	.17	42.1	38.7	30.2	.21
Personnel shortages/time constraints (%)	38.0	43.6	35.6	40.8	.48	28.4	29.3	50.0	.002
Lack of knowledge about palliative care by health care professionals (%)	37.7	29.0	41.2	32.7	.17	37.2	41.3	35.4	.73
Communication difficulties between health care professionals and patients/families (%)	33.9	21.0	34.5	36.7	.10	28.4	38.7	30.2	.32
Communication difficulties among health care professionals (%)	32.2	33.9	32.0	30.6	.92	16.7	41.3	45.8	<.001

Discussion

Health care personnel in rural Colorado and Kansas reported that they are effective in treating dying patients and that most are satisfied with the palliative care being provided. Most also reported that the palliative care could be improved. Although this may seem paradoxical, McConigley et al¹⁷ also found that rural Australian health care professionals not only report high confidence levels in their ability to provide palliative care services but also express high levels of interest in palliative care education, increased support, and assistance in palliative care practice. This apparent contradiction may not only be reflective of the demands of the health care system in rural settings where providers tend to work in isolation and with limited consultation and resources but may also be reflective of an understanding by rural providers of the need for continuing education and support in a rapidly changing medical field.¹⁷

Our findings highlight that differences exist in the perceptions of palliative care delivery by clinicians, nurses, and medical assistants. Hence, both training and experience may influence beliefs toward the care provided.

Barriers to providing optimal palliative care in rural Colorado and Kansas are similar to those previously reported in the literature^{15,19,21-25} and to those existing in urban facilities, as reported from a study that used a similar survey instrument.²¹ Our study, however, found that only family members' avoidance of issues of dying was commonly perceived as a barrier by the majority of respondents. It is possible that by giving respondents a list of barriers, we may have limited our findings of other potential barriers. Although respondents were asked to write in any barrier to providing optimal palliative care, this seldom elicited responses that were not already provided. Future studies using qualitative methods such as focus groups or individual interviews may help elicit other potential barriers to providing care in rural areas.

Furthermore, our results may not generalize to other regions. However, from our knowledge and experience with these rural communities, we believe that our results likely represent the general attitudes and beliefs in these areas. In addition, we did not obtain the patient or family perspective. The patient and patient's family remain integral in the coordination of optimal care and the decision making process; therefore, their perspectives of perceived barriers to optimal end-of-life care in rural areas need to be better understood.

Efforts to improve the care of dying patients in rural settings must take into account the perceptions of all health care personnel who provide care. By surveying health care personnel from multiple types of facilities within 2 rural practice-based research networks, our study allowed us to describe and compare responses across health care personnel's roles and types of facilities where care is delivered. Results of this study suggest that it may be important to customize and tailor the educational and support service interventions to all health care personnel who participate in palliative care in the rural communities and at all facilities where care is provided. Rural health care facilities may want to find ways to offer such services or work in combination with other communities and existing hospice organizations to share expertise and resource availability in order to provide the best care possible to the rural dying patient.

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