Brief Report

A Comparison of Rural and Urban Hospice Family Caregivers' Cancer Pain Knowledge and Experience

Karla T. Washington, PhD, Debra Parker Oliver, PhD, Jamie B. Smith, MA, Robin L. Kruse, PhD,
Salimah H. Meghani, PhD, and George Demiris, PhD
Department of Family and Community Medicine (K.T.W., D.P.O., J.B.S., R.L.K.), University of Missouri, Columbia, Missouri; School of Nursing (S.H.M.), University of Pennsylvania, Philadelphia, Pennsylvania; and Schools of Nursing and Medicine (G.D.), University of Pennsylvania, Philadelphia, Pennsylvania, USA

Abstract

Context. Family caregivers play a vital role in managing the pain of hospice patients with cancer; however, caregivers' knowledge of pain management principles and experiences as pain managers vary widely. Differences in cultural values and access to resources suggest that rural and urban hospice family caregivers may differ with regard to their pain knowledge and experience, but this has not been empirically investigated.

Objectives. We sought to determine if rural and urban hospice family caregivers differed in terms of their knowledge of cancer pain management principles and their experiences managing cancer pain.

Methods. Our study consisted of a secondary analysis of baseline, cross-sectional data from hospice family caregivers ($N = 196$) participating in an ongoing cluster randomized crossover pragmatic trial. We performed multivariable regression to model associations between caregivers' demographic characteristics and their scores on the Family Pain Questionnaire (FPQ), which included subscales measuring pain knowledge and experience.

Results. When controlling for other demographic variables, rural caregivers' scores on the FPQ knowledge subscale were worse ($P = 0.01$) than their urban counterparts. FPQ experience subscale scores and FPQ total scores were not statistically significantly different between the two groups.

Conclusion. Rural hospice family caregivers report greater pain knowledge deficits than urban hospice family caregivers, although the two groups report comparable pain management experiences. Additional research is needed to better explain observed differences. J Pain Symptom Manage 2019;58:685—689. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Cancer, caregivers, hospice care, pain, rural, urban

Introduction

Each year, over half a million Americans with advanced cancer elect to receive hospice services when disease-directed therapies are ineffective and life expectancy is limited.[1] Hospice is a specialized type of end-of-life care in which an interdisciplinary team of professional partners with patients and their family members to control pain and other distressing symptoms. Despite receipt of specialized care, many hospice patients with cancer suffer from poorly controlled symptoms[2,3]; over 50% experience moderate-to-severe levels of pain in their final week of life.[4]

Family caregivers (FCGs) are unpaid family members and friends responsible for the majority of care provided to U.S. hospice patients, most of whom receive services in the community rather than an inpatient hospice unit.[1] A robust body of research documents the numerous challenges FCGs face related to

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Address correspondence to: Karla T. Washington, PhD, MA 306, Medical Sciences Bldg. DC032.00, Columbia, Missouri 65212, USA. E-mail: washingtonkar@health.missouri.edu

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pain management.[5–9] FCGs frequently express discomfort administering pain medications, fearing undermedicating or overmedicating patients.[7,9,10] They struggle to assess pain[5] and worry about pain medications' side effects such as confusion, sedation, and constipation.[7,9,10] Many report challenges communicating with health care providers about pain.[11] FCGs who witness uncontrolled pain are often highly distressed[12] and are at increased risk for poor long-term outcomes such as social role impairment, decreased energy, negative perceptions of general health, and major depressive disorder.[13]

Pain Management in Rural Communities

A number of factors make hospice pain management particularly challenging in rural communities.[14] Rural patients' homes may be located at long distances from agency offices, resulting in significant staff time and mileage costs associated with home visits, potentially deterring unscheduled in-home support to address pain crises.[15] A culturally sanctioned desire not to inconvenience others (not to "be a bother"), an emphasis on self-sufficiency, a preference for informal vs. professional support systems, and widespread support for stoicism in the face of pain[16,17] can lead rural FCGs to feel disinclined to access 24-hour support that is available from all Medicare-certified hospice agencies.[18] Rural FCGs may view pain medications as inherently dangerous, and they will likely have been exposed to the pervasive social stigma related to opioid use,[19] which is particularly pronounced in rural communities that have been disproportionately affected by the current opioid crisis.[20,21] Furthermore, maintaining privacy about one's health is often challenging in rural areas,[22] and news that someone is receiving home hospice care may signal to others the likely presence of opioids in the home, introducing both security concerns and the potential for negative reactions from influential others.[23] Rural communities also tend to have limited access to professional personnel (particularly specialty-trained hospice and palliative care professionals), fewer community services (e.g., 24-hour pharmacy services), and a limited supply of in-home personal care providers.[15] Taken together, these factors seem likely to result in rural hospice FCGs having less knowledge about pain management principles and worse pain management experiences; however, this has not been empirically investigated.

Study Purpose, Research Questions, Hypotheses

The purpose of this study was to compare rural and urban hospice FCGs' cancer pain knowledge and experience. Our specific research questions (RQs) and corresponding hypotheses (Hs) were as follows:

RQ1: Do rural and urban hospice FCGs differ in terms of their knowledge of pain management principles?

H1: Rural hospice FCGs will report less knowledge of cancer pain management principles than their urban counterparts.

RQ2: Do rural and urban hospice FCGs differ with regard to their experiences managing cancer pain?

H2: Rural hospice FCGs will report poorer quality experiences managing cancer pain than hospice FCGs in urban areas.

Methods

All research activities were conducted as a substudy of an ongoing cluster randomized crossover pragmatic trial sponsored by the National Cancer Institute (R01CA203999; henceforth referred to as the "parent trial"). The parent trial was approved by leadership of the participating hospice agencies and the University of Missouri Institutional Review Board (#2006270). The full study protocol is registered at clinicaltrials.gov (NCT02929108). Study participants were adult FCGs of adult patients with cancer who were receiving services from one of six hospice agencies in the Midwestern United States. FCGs were recruited into the parent trial as close as possible to the date of their patient's hospice enrollment; most (74%) joined the study within two weeks of the hospice enrollment date.

Data Source

Upon providing consent to participate in the parent trial, FCGs provided basic demographic information and completed several standardized instruments via REDCap (Research Electronic Data Capture), a secure Web application for survey administration.[24] Among these instruments was the Family Pain Questionnaire (FPQ), which comprised two subscales: one measuring FCGs' knowledge of cancer pain management principles (nine items; total scores range from 0 to 90), and the other measuring the quality of caregivers' pain management experiences (seven items; total scores range from 0 to 70).[25] FCGs completing the FPQ provided a numeric response using a scale from 0 (the most positive outcome) to 10 (the most negative outcome). A sample item from the FPQ knowledge subscale read, "Most cancer patients on pain medicines will become addicted to the medicines over time" (0 = disagree, 10 = agree). A sample item from the FPQ experience subscale read, "How distressing is your family member's pain to you?" (0 = not at all, 10 = a great deal). Psychometric analyses have supported the FPQ's test-retest reliability;

internal consistency; and content, construct, and concurrent validity.[25] To minimize any potential effects of participation in the parent trial, only data collected at the time of study enrollment were included in the present analysis.

Data Analysis

We assigned participants' home addresses to residence in a rural (i.e., outside of a Metropolitan Statistical Area or MSA, as determined by the U.S. Office of Management and Budget[26]) or urban (i.e., inside an MSA) area. Then, after conducting bivariate analyses to confirm there were no statistically significant demographic differences between the two groups, we used multivariable regression models to assess the associations between FCGs' characteristics (age, gender, education, residence within one hour from patient or not, and rural or urban location) and the FPQ knowledge subscale score, the FPQ experience subscale score, and the FPQ total score. We examined these specific characteristics owing to their availability in the existing data set, relevance to our study's research questions, and prior research on sociodemographic differences in barriers to pain management[27,28] and challenges associated with long-distance caregiving.[29] All analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC).

Results

The study included 196 FCGs (Table 1). FCGs had a mean age of 56 years, and most (76%) identified as female. The vast majority (90%) were Caucasian, and 37% reported having a college degree or higher. Slightly more than half (53%) reported either coresiding or living within one hour from the patient. FCGs were mostly either adult children (44%) or spouses/partners (31%). A majority (67%) lived in an urban area.

Multivariable regression analyses are presented in Table 2. When including all the predictor variables in the model, FPQ knowledge subscale scores were higher/worse ($P = 0.01$) for rural caregivers (mean [M] = 42.15, SD = 13.31) than caregivers in urban areas (M = 38.19, SD = 12.57); however, rural (M = 30.81, SD = 12.35) and urban (M = 33.03, SD = 14.82) caregivers' scores on the FPQ experience subscale were not statistically significantly different ($P = 0.49$). FPQ total scores for rural (M = 73.71, SD = 17.98) and urban (M = 72.32, SD = 19.70) caregivers were also not statistically significantly different.

Discussion

As hypothesized, rural hospice FCGs reported greater pain knowledge deficits than urban hospice FCGs; however, contrary to our hypothesis, the two groups reported pain management experiences of similar quality. This unexpected result is particularly surprising given that knowledge deficits have been consistently identified as a barrier to effective pain management.[5] We would, thus, have expected identified differences in pain knowledge to be mirrored in similar differences with regard to pain experience, but this was not the case in our analysis. While we cannot know for sure, it is possible that caregivers'

Table 1
Participant Demographics

	Total, *N* (%)	Rural, *n* (%)	Urban, *n* (%)	*P*-value[a]
Sample size	196 (100.0)	64 (32.7)	132 (67.4)	
Age, mean (SD)	56.3 (11.9)	64 (58.0)	132 (55.6)	0.21
Gender				0.23
Male	47 (24.0)	12 (25.5)	35 (74.5)	
Female	149 (76.0)	52 (34.9)	97 (65.1)	
Race				0.20
Black	16 (8.2)	1 (6.3)	15 (93.8)	
White	177 (90.3)	62 (35.0)	115 (65.0)	
Other	3 (1.5)	1 (33.3)	2 (66.7)	
Education				0.14
No degree	122 (62.2)	44 (36.1)	78 (63.9)	
Degree (≥undergraduate)	73 (37.2)	19 (26.0)	54 (74.0)	
Relationship to patient				0.09
Spouse or partner	61 (31.1)	26 (42.6)	35 (57.4)	
Parent	16 (8.2)	7 (43.8)	9 (56.3)	
Adult child	87 (44.4)	21 (24.1)	66 (75.9)	
Other (e.g., sibling, in-law, etc.)	32 (16.3)	10 (31.3)	22 (68.8)	
Residence				0.60
Lives with or ≤ 1 hour from patient	104 (53.1)	33 (31.7)	71 (68.3)	
Lives > 1 hour from patient	85 (43.4)	30 (35.3)	55 (64.7)	

[a] *P*-value based on chi-square or t-statistic comparison between rural and urban groups.

Table 2
Multiple Regression Models for Family Pain Questionnaire (FPQ) Scores

Model	Parameter Estimate (95% CI)	Standard Error	*P*-value
Knowledge Subscale			
Age	−0.05 (−0.21 to 0.10)	0.08	0.48
Gender (female vs. male)	−8.15 (−12.5 to −3.76)	2.22	0.0003
Education (degree vs. none)	−3.44 (−7.34 to 0.45)	1.97	0.08
Residence (w/in 1 hr vs. not)	−2.04 (−5.81 to 1.73)	1.91	0.28
Location (urban vs. rural)	−4.96 (−8.91 to −1.01)	2.00	0.01
Experience Subscale			
Age	−0.25 (−0.44 to −0.07)	0.09	0.005
Gender (female vs. male)	−2.41 (−7.28 to 2.45)	2.46	0.32
Education (degree vs. none)	0.48 (−3.90 to 4.86)	2.21	0.82
Residence (w/in 1 hr vs. not)	−0.00 (−4.28 to 4.28)	2.17	0.99
Location (urban vs. rural)	1.54 (−2.89 to 5.99)	2.25	0.49
Total FPQ			
Age	−0.22 (−0.48 to 0.03)	0.13	0.08
Gender (female vs. male)	−9.34 (−16.0 to −2.67)	3.38	0.006
Education (degree vs. none)	−3.36 (−9.37 to 2.64)	3.04	0.27
Residence (w/in 1 hr vs. not)	−3.25 (−9.08 to 2.58)	2.95	0.27
Location (urban vs. rural)	−2.75 (−8.86 to 3.34)	3.09	0.37

Model statistics: Knowledge ($R^2 = 0.12$, F (5,172) = 4.45, $P = 0.0008$); Experience ($R^2 = 0.05$, F (5,176) = 1.99, $P = 0.08$); Total FPQ (R^2 F (5,166) = 2.67, $P = 0.02$).

responses with regard to their pain experiences were shaped by their cultural values. For example, stoic attitudes[17] may have led rural caregivers to assess their family member's pain as less intense or distressful than an urban caregiver would have in a similar situation.

There is very little extant research on rural-urban differences in hospice outcomes with which to compare our results. However, a 2015 study conducted in the Southeastern United States found that rural hospice patients and families reported greater satisfaction with pain and symptom management than those residing in urban communities.[15] The authors of that study suggested that rural communities' greater connectedness might play a role in higher satisfaction ratings among rural patients and families. These strong social ties might also afford hospice patients considerable comfort despite the physical realities of their illness. Clearly, however, more research is needed to examine these possibilities.

Several study limitations further highlight the need for additional research. Data analyzed in this cross-sectional study were collected shortly after hospice enrollment. Although the length of hospice service is fairly brief for patients with cancer (the average number of days for Medicare beneficiaries was 48 in 2017[30]), we cannot be certain that these results would be the same if the data were collected later. In addition, the generalizability of our results is further limited by our sample's lack of diversity with regard to race, gender, and geographic region of the U.S. Finally, there are many different ways to measure rurality. Given our limited sample size, we conceptualized rurality as a dichotomous construct; however, future studies with larger samples will likely be strengthened by consideration of rurality as existing on a continuum, as is possible by application of the U.S. Department of Agriculture's Rural-Urban Continuum Codes,[31] for example.

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