

**Exploring Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and
Adults Using a Convergent Parallel Design**

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Abstract

Purpose: To explore the palliative care perceptions of rural dwelling providers, nurses, and adults and, to explore the relationship between the knowledge and perceptions of palliative care held by rural providers and nurses, using a convergent parallel design.

Sample: Qualitative (n = 25), Quantitative (n = 51)

Methods: The setting was a geographically defined rural area of 8,500 square miles. Following institutional review board approval, providers (n = 5), nurses (n = 7), and adults (n = 13),

completed a demographic survey and audio-recorded, face-to-face, semi-structured interviews. Qualitative data were analyzed using thematic analysis following a loosely grounded theory approach that was comprised of multiple rounds of coding assisted by qualitative analysis software. Survey packets were delivered to 19 healthcare organizations in the same geographic study area; 51 participants (providers, $n = 7$; nurses, $n = 44$) completed a demographic survey and the 20-item Palliative Care Knowledge Test (PCKT). Both qualitative and quantitative data were analyzed separately before merging and comparing the results in a final analysis.

Results: Six themes were identified: Palliative care offers comfort for the dying or end-of-life care; Palliative care? Never heard of it; Uncertainty about the differences between palliative care and hospice; Conflicts between theory and practice; Timing is everything; and Experience is a strong teacher. PCKT total scores for the sample of providers and nurses ($n = 51$) was 10.73 ($SD 2.93$) which suggested poor palliative care knowledge. After merging the results, the final analysis indicated convergence. Two constructs, Maturity and Rural Investment, were identified.

Conclusion: Providers and nurses in rural areas are experienced, having lived and practiced in rural areas for a considerable time; supporting the constructs of Maturity and Rural Investment. Misperceptions and poor knowledge related to palliative care likely prevent the broader application of palliative care in rural areas.

Keywords: palliative care, rural, providers, nurses, perceptions, convergent parallel design

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Introduction

Palliative care is focused on improving the quality of life of people suffering from life-threatening acute or chronic illnesses and is as appropriate for a teenager undergoing cancer treatments as it is a 94-year-old at the end-of-life (Meier & Bowman, 2017). The World Health Organization (WHO) defines palliative care as the following:

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. (2018, Para. 1)

WHO (2018) has deemed palliative care a basic human right capable of relieving the suffering that accompanies many chronic illnesses, such as multiple sclerosis, rheumatoid arthritis, dementia, and cancer. Palliative care can be introduced at any point in the disease trajectory, from diagnosis through the end-of-life. Despite advances in the understanding and availability of palliative care, many people who live in rural areas lack access to healthcare services including palliative care (Bolin et al., 2015). People living in rural areas experience a shortage of physicians and nurses, have smaller incomes, are less healthy, and have less access to health care services, including palliative care, than those who reside in urban areas (Bolin et al., 2015). Additionally, rural dwelling people are more likely to be uninsured (Bolin et al., 2015) or covered by a by a high

deductible health plan (Leonardson, Ziller, & Coburn, 2014), which may further limit access to health care services.

By 2030, one out of five Americans will be 65 years of age or older (Centers for Disease Control and Prevention [CDC], 2013), and most of these individuals will be living with multiple chronic conditions (Gerteis et al., 2014). Adults living with serious chronic conditions often experience a decreased quality of life (CDC, 2013). Concurrent palliative care, which is palliative care offered at the same time as usual or curative treatment, has been reported to improve the quality of life for people living with heart failure (Dionne-Odom et al., 2014) and cancer (Doyle, 2017). However, a significant barrier to the implementation of concurrent palliative care may be the perception that palliative care is end-of-life or hospice care held by physicians (LeBlanc et al., 2015) and nurses (Aslakson et al., 2013). Although progress has been made in improving undergraduate medical education, teaching around the concept of palliative care is delivered almost exclusively by lectures and seminars, and supported mainly through hospice visits (Fitzpatrick, Heah, Patten, & Ward, 2017). The application of the concept of palliative care as a process of improving the quality of life for individuals across the life span, to prevent and relieve suffering given life-threatening illness, is limited.

Researchers conducting a mixed methods study of 66 oncologists at three academic cancer centers, one of which was in a predominantly rural state in the United States (U.S.), found that the majority of the 23 hematologic oncologists perceived palliative care to be end-of-life care (61%). The study also showed that 43% had never referred a patient with advanced cancer to palliative care (LeBlanc et al., 2015). Authors of a qualitative study that included 38 urban and rural physicians, nurses, and adults in Germany reported that palliative care was perceived as end-of-

life care, and inappropriate for conditions with uncertain disease trajectories; furthermore, the adults could not perceive as to how palliative care might be helpful (Golla, Galushko, Pfaff, & Voltz, 2014). Similar findings were revealed by a qualitative study conducted in the U.S which involved 18 urban and rural providers treating heart failure; palliative care was perceived as end-of-life care and unsuitable for conditions with uncertain trajectories (Kavalieratos et al., 2014). In a qualitative study conducted in Australia involving 94 emergency physicians and nurses, including staff from regional hospitals serving rural areas, researchers reported that participants perceived palliative care to be end-of-life care, appropriate after treatment ends, and to conflict with life-saving measures (Weil et al., 2015). Upon diagnosis with a serious health condition, patients are informed by providers about future treatment options. According to the authors of a study conducted in the Netherlands, 16 nurses perceived that palliative care should start as soon as the treatment ends (Verschuur, Groot, & van der Sande, 2014) and to that end, nurses spend the most time with patients.

In rural areas, nurses are often asked for advice outside of working hours (Lee & McDonagh, 2013) and are consulted by families, friends, and community members. One quantitative study of palliative care knowledge among rural nurses ($n = 33$) at three long-term care facilities in rural Kentucky using the Palliative Care Knowledge Test (PCKT) found low knowledge scores (49% correct). This study concluded that more palliative care education was needed to improve the care and quality of life for rural long-term care residents (Evans, 2016). Providers' and nurses' palliative care perceptions and knowledge when combined with experiences with rural providers and rural nurses, likely impact how adults living in rural areas perceive palliative care.

Palliative care, when offered as a critical component of comprehensive primary care in rural areas, may allow rural adults with serious chronic conditions to have an improved quality of life, remain active for a longer period, and possibly age in place. Exploring and comparing palliative care perceptions among rural dwelling providers, nurses, and adults is the first step to understanding rural palliative care needs and bringing about transformative change in healthcare delivery models applied to rural areas.

A qualitative study conducted in Australia involving 20 Aboriginal women with breast cancer and their care providers reported negative perceptions of palliative care as isolating, culturally insensitive, end-of-life care, and based on experiences (Dembinsky, 2014). Correspondingly, a qualitative study involving 50 adults conducted in a largely rural area of Northern Ireland showed that adult varying perceptions of palliative care were based on several influences, including the media (McIlfatrick et al., 2014). Whether positive or negative, perceptions of palliative care are likely to be reinforced by rural adult experiences (Dembinsky, 2014; McIlfatrick et al., 2014). However, it is possible to change the perceptions of palliative care with education (Kozlov, McDarby, Reid, & Carpenter, 2017; McIlfatrick et al., 2014).

Based on a comprehensive review of current research and related literature, palliative care perceptions have not been exclusively studied in rural dwelling providers, nurses, and adults within the U.S. Most of what we know about the perceptions of palliative care is based on research studies conducted in urban or rural areas outside of the U.S. It may be noted that little published research exists related to the perceptions of palliative care among rural adults. Therefore, the purpose of this research was to explore the palliative care perceptions among rural dwelling providers, nurses, and adults. A convergent parallel design was used to explore the perceptions of palliative care

among rural providers, nurses, and adults. A mixed methods research approach combines the strengths of quantitative and qualitative research designs while overcoming limitations, thereby strengthening the analyses (Creswell, 2014).

Study Aims

This mixed methods study had two specific aims. The primary aim was to explore and compare palliative care perceptions among rural dwelling providers, nurses, and adults. For this study, providers were defined as medical doctors (MDs), osteopathic doctors (DOs), nurse practitioners (NPs), and physician assistants (PAs). Nurses were defined as licensed practical/licensed vocational nurses (LPNs/LVNs) and registered nurses (RNs) who were not licensed as advanced practice nurses. Rural dwelling adults were defined as people, age 18 or older, who were not actively employed as providers or nurses, and who were living in one of the four rural counties where the study was conducted. The secondary aim was to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses practicing in rural areas.

The significance of this study for all providers, but specifically to nurses, is in the context of gaining new knowledge to (1) promote outcome-focused discussions about rural dwelling adults and palliative care; (2) assist health service planners and others involved in designing and improving health care for rural dwelling adults; (3) transform palliative care education; and (4) transform practice models. Understanding the perceptions of palliative care is the first step to beginning dialogues about improving the access to palliative care, specifically concurrent palliative care, in rural areas.

Theoretical Framework

Rural nursing theory provides the conceptual framework for this study. The underlying concepts in rural nursing theory are centered on *rural dwelling people and how health is defined as the ability to be productive, to do, and not necessarily as the absence of disease* (Long & Weinert, 2013). Rural nursing theory was introduced in 1989 by Long and Weinert as an outcome of a qualitative exploration of living by rural dwelling people (Winters, 2013). Other key concepts of rural nursing theory that serve as the premise of this study include self-reliance and autonomy, delayed healthcare seeking behaviors, and healthcare professionals as generalists (Lee & McDonough, 2013; Scharff, 2013) who experience role diffusion and lack anonymity (Lee & McDonough, 2013). The way rural dwelling adults define health impacts how they seek health care and prefer to live. Similarly, how providers and nurses practice in rural areas, their education, knowledge, and experiences, likely influence their perceptions of palliative care.

Methods

This mixed methods study used a convergent parallel design. Qualitative and quantitative data were collected simultaneously, analyzed separately, and merged and compared in the final analysis (Clark & Ivankova, 2016). The qualitative data were analyzed prior to the quantitative data to avoid introducing bias during the qualitative analysis.

Setting

The setting included four rural counties situated in the western U.S., encompassing over 8,500 square miles. Providers and nurses working at 19 healthcare organizations within the same geographic area participated in the quantitative component of the study. The four counties within the geographic area are sparsely populated, ranging from 2.5 to 5.3 people per a square mile and

are classified as mostly rural and completely rural in accordance to the County Classification Lookup Table (United States Census Bureau, n.d.). Rural is defined as areas that are not classified as urban or urban clusters (Ratcliffe, Burd, Holder, & Fields, 2016; United States Census Bureau, n.d.).

Sample

Qualitative component. A purposive sampling scheme was used in this study. Newspaper advertisements, word-of-mouth, as well as posters placed on community and rural message boards were used within the defined geographic area to recruit participants who were over the age of 18 years, could speak and understand English, and lived in one of the states/counties of interest. To avoid the possibility of significant emotional distress arising from the interview questions, the study excluded the participation of adults who had experienced the death of a close family member or friend within the past six months, had a close family member/friend diagnosed with a terminal illness in the past six months, or who had received a terminal diagnosis. Potential participants were screened using the inclusion/exclusion criteria and read information from the consent form. Audio-recorded, semi-structured interviews were conducted at mutually agreed upon locations by one interviewer using a semi-structured interview guide. Field notes and memos were completed and labeled with the participants' assigned number. In this context, notes and memos are helpful in completing thick descriptions and performing qualitative data analysis (Glesne, 2016). A total of 29 potential participants were screened, and four were excluded after reporting deaths of family members or close personal friends within the past six months. The final qualitative sample ($n = 25$) included five providers, seven nurses, and 13 adults.

Quantitative component. An *a priori* sample estimation was conducted using G*Power Version 3.1.9.2 (Faul, Erdfelder, Lang & Buchner, 2007) to determine the total sample size ($n = 128$) needed based on parameters for a two-tailed t-test, 0.80 power, a medium effect size of 0.50, and two independent groups, rural providers ($n = 64$) and rural nurses ($n = 64$). Study packets were provided to each of the 19 healthcare organizations. Practice organizations included small public and private clinics, hospitals, skilled nursing and assisted living facilities, and home health services. After reading the information sheet contained in the packet, interested providers and nurses completed a short pen-and paper demographic survey in addition to the Palliative Care Knowledge Test (PCKT). Surveys were returned to the researcher using a prepaid, pre-addressed envelope provided within the study packet.

Ethical Considerations

Ethical approval for this study was obtained from the Human Subjects Committee of the research institution (study #FY2018-38). Potential participants were provided information about the voluntary study as part of the screening process. Signed consents were obtained prior to the interviews. No identifying information was collected on the quantitative surveys. A Subway® gift card worth \$10 was offered to all participants as an acknowledgment of their time.

Instrumentation

Demographics. Thirteen demographic questions were asked of all participants: gender, marital status, ethnicity, race, birth year, zip codes of home and work, total number of years of having lived rurally, total number of years lived in current zip code, education level, employment status, job, and veteran status. Providers and nurses were asked additional questions about primary

practice setting, main area of specialization, years of experience, completion of palliative care training, and palliative care certification.

Semi-Structured Interview Guide. An interview guide (see Figure 1) was developed from a review of the literature and reviewed by an expert panel. Questions appropriate for each group, defined by columns, were noted with an “x”. Questions that were not applicable to a group were noted by a darkened cell. The interview guide contains the questions asked of all participants (bolded) and sample questions asked of some of the participants based on individual responses to initial interview guide questions (Figure 1).

Palliative Care Knowledge Test (PCKT). The PCKT is a questionnaire developed by researchers in Japan to assess the palliative care knowledge of nurses and providers (Nakazawa et al., 2009). Use of the PCKT was reported in one study conducted with rural nurses in the U.S. (Evans, 2016). Nakazawa and colleagues (2009) reported validation of the PCKT with nurses ($n = 940$) at two different facilities in Japan. The PCKT aligns with the WHO’s current definition of palliative care and consists of 20 questions assigned to one of five domains associated with palliative care: philosophy (2 questions), pain (6 questions), psychiatric problems (4 questions), and gastrointestinal problems (4 questions). Three response choices, “true”, “false” and “unsure”, are available to the participants for each question. One point is awarded for each correct response, and the maximum attainable score is 20. Higher scores are indicative of greater palliative care knowledge. The instrument has a reported internal consistency of 0.81 with the domain internal consistency ranging from 0.61 to 0.82, and test-retest correlation of 0.88 (Evans, 2016; Nakazawa et al., 2009).

Semi-Structured Interview Guide – Rural Dwelling Providers, Nurses, and Adults

	Providers	Nurses	Adults
What does health mean to you or how do you define health?	X	X	X
Have you heard of, or are you familiar with the term palliative care?	X	X	X
What is palliative care? – or- How would you define palliative care?	X	X	X
What type of conditions are appropriate for palliative care?	X	X	X
Where is palliative care delivered?	X	X	X
When is the most appropriate time for palliative care?	X	X	X
Have you had training in palliative care?	X	X	
What is hospice?	X	X	X
Do you think palliative care and hospice are the same? Different? Please explain.	X	X	X
Have you or anyone you know experienced palliative care? Please tell me about that.	X	X	X
Do you are anyone you know have a serious health condition? Please tell me about that.			X
What types of things do you (or do they) worry about related to (serious health condition)?			X
Do you (or the person named) have any bothersome symptoms that make it difficult to do things?			X
How does this impact your life (their life)?			X
Is there anything else that you would like to add that we did not get a chance to discuss?	X	X	X

Figure 1. Semi-Structured Interview Guide

Qualitative Analysis

Qualitative analyses addressed the primary aim of the research to explore and compare palliative care perceptions among rural dwelling providers, nurses, and adults. Qualitative analysis software, Atlas.ti, version 7.5.15 (ATLAS.ti Scientific Software Development GmbH, 2016) was used to assist with data analysis. The analysis of data was undertaken using thematic analysis, which supported the development of themes while staying grounded in the data. Thematic analysis as an independent method of qualitative analysis has been supported by colleagues in field of psychology (Braun & Clarke, 2008).

Three rounds of coding were conducted as part of the qualitative analysis. To become immersed in the data, all audio-recordings were carefully listened to following the interviews. The interviews were listened to a second time prior to beginning the preliminary coding process. The

preliminary coding process involved the identification of key ideas or codes (inductive), to serve as initial codes (deductive) for the remaining interviews. The first three interviews were coded independently by two researchers (TT, SST), who met twice via ZOOM video conferencing technology to discuss the initial codes and preliminary findings. Subsequent interviews were coded by one researcher (TT), adding more codes in the process. The second researcher was available throughout the process to provide the opportunity to critically discuss and debate emerging themes. After all twenty-five interviews underwent preliminary coding, the audio-files were listened to again, and nearly identical codes were merged where appropriate. Upon merger, the codes related to a similar idea or experience were grouped together into code families. The final round of coding entailed the use of code families and memos to identify themes and subthemes based on the frequency, the number of times the code/code family appeared across interviews. Exemplar quotes were identified to support each key theme.

Quantitative Analysis

Quantitative analyses served to explore palliative care knowledge among rural providers and nurses in support of the secondary research aim, to explore the relationship between knowledge and perceptions of palliative care among providers and nurses. A total of 53 surveys were received. Two surveys were not completed by providers or nurses and were excluded. The results of the remaining 51 surveys met the inclusion criteria and were included in the analyses.

Data were shared with co-authors and the third author served as the statistical consultant. Analyses were performed using SPSS Version 23. Data were first reviewed for missing data. Missing demographic data were analyzed based on the number of participants who provided a response. In one instance, a response was missed for PCKT Question 10, and it was determined

to be missing completely at random; no other questions were skipped. Missing data between two and five percent is considered acceptable (Meyers, Gamst, & Guarino, 2013; Vogt, Vogt, Gardner, & Haeffele, 2014) and was not exceeded in this study. The decision was made to estimate a response as the missing value accounted for two percent, the sample was small, and lower powered nonparametric tests were used (Polit, 2010). After analyzing the remaining responses to Question 10 ($n = 50$), most responses were found to be either incorrect or “unsure” (54%, $n = 27$). Therefore, the value of “unsure”, with no point value, was assigned to resolve the missing datum.

Categorical level demographic data were analyzed using frequency counts and percentages and scale level data were analyzed using mean, standard deviation (SD), skewness, and kurtosis. Statistical significance was set to $p < .05$ for all tests. Effect size, which was calculated using Spearman’s rho, was used to explore correlations between PCKT Total Scores and age, years of experience, years lived in the area of current zip code, and the total number of years lived rurally, and to analyze the correlations between the five PCKT domains. The use of Spearman’s rho is appropriate with ordinal level dependent variables, such as PCKT Total Score, small sample sizes, and in instances when outliers are present (Polit, 2010). Descriptive statistics, frequency counts and percentages, were used to compare PCKT individual question scores between the rural provider group and the rural nurse group. The Mann-Whitney U test was used to ascertain the differences in the ranks of PCKT Total Scores and PCKT Domain Scores between the rural provider, as well as the rural nurse group and the ranks in PCKT Total Scores and Domains Scores between respondents who had reported completing some form of palliative care education, and those who had not. Using optimal scaling with multiple nominal data, exploratory categorical

principal components analysis (CATPCA) was conducted to explore constructs that could explain the total variation (Meyers et al., 2013) in PCKT scores.

Convergent Analysis

Qualitative and quantitative results were merged in the final analysis and addressed the secondary study aim to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses practicing in rural areas. Notably, the themes identified in the qualitative analysis were used to inform the quantitative PCKT results or palliative care knowledge results. The qualitative and quantitative results of convergent parallel design studies are reported in the results section and the convergent analysis, which is the result of merging and comparing both qualitative and quantitative results, is presented in the discussion section (Creswell, 2014).

Results

Qualitative

Twenty-five rural dwelling participants, providers ($n = 5$), nurses ($n = 7$), and rural adults ($n = 13$), completed the audio-recorded, face-to-face, semi-structured interviews. Sample characteristics are depicted in Tables 1 and 2. Actual interview times ranging from six to 26 minutes were conducted at a variety of locations, including places of employment, libraries and the homes of participants. Six major themes were eventually identified.

Table 1.

Rural Participants by Group: Gender, Marital Status, Education, and Employment

	Providers $n = 5 / n = 7$ n (%)	Nurses $n = 7 / n = 44$ n (%)	Adults $n = 13$ n (%)
Gender	<u>Qualitative</u>	<u>Quantitative</u>	<u>Qualitative</u> <u>Quantitative</u>

Males	3 (60)	4 (57)	1 (14)	4 (9)	7 (54)
Females	2 (40)	3 (43)	6 (86)	40 (91)	6 (46)
Marital Status					
Married	4 (80)	6 (86)	6 (86)	30 (68)	11 (85)
Education					
HS Graduate/GED					4 (31)
Some College			1 (14)	3 (7)	1 (8)
Associates			4 (57)	26 (59)	3 (23)
Bachelors		1 (14)	2 (29)	11 (25)	4 (31)
Graduate	5 (100)	6 (86)		4 (9)	1 (8)
Employment					
>35 hours per week	5 (100)	7 (100)	7 (100)	41 (93)	2 (15)
<35 hours per week				3 (7)	3 (23)
Not Employed					8 (62)
Primary Practice Setting					
Hospital	3 (60)	2 (29)	5 (71)	31 (70)	
Clinic	2 (40)	5 (71)		7 (16)	
SNF ^a			2 (29)	3 (7)	
Home Care				3 (7)	
Employed Position					
MD/DO	2 (40)				
NP	3 (60)	5 (71)			
PA		2 (29)			
RN			6 (86)	35 (80)	
LPN			1 (14)	9 (20)	
PC Training					
No	4 (80)	5 (71)	6 (86)	36 (82)	
Yes	1 (20)	2 (29)	1 (14)	7 (16)	
Did not Answer				1 (2)	

Note: Due to the differences in rounding, percentages may not equal 100. ^aSNF is Skilled Nursing Facility; ^bPC Training is Palliative Care Training.

Table 2.
Rural Participants by Group: Age, Years of Rural Living, and Provider and Nurse Years of Experience

	Providers <i>n</i> = 5 / <i>n</i> = 7 <i>M</i> (<i>SD</i>)		Nurses <i>n</i> = 7 / <i>n</i> = 44 <i>M</i> (<i>SD</i>)		Adults <i>n</i> = 13 <i>M</i> (<i>SD</i>)
	Qualitative	Quantitative	Qualitative	Quantitative	
Age (years)	51 (11.9)	50 (12.4)	48 (9.2)	43 (11.4)	65.3 (7.4)
Rural (years) ^a	37 (14.0)	41 (16.3)	28 (18.8)	29 (15.9)	49.5 (21.5)
Current (years) ^b	15 (12.2)	13 (13.3)	7 (6.4)	14 (13.9)	19.4 (18.7)
Experience (years)	15 (15.0)	17 (15.1)	14 (10.7)	15 (11.8)	

Note: Due to the differences in rounding, percentages may not equal 100. ^aTotal number of years lived rurally over life; ^bTotal number of years lived in current zip code (postal code)

A picture of the rural environment. Prior to discussing the key themes, it is important to get a picture of the environment and healthcare facilities employing the nurses and providers who were interviewed. The environment is quite rugged, ranging from open, unprotected plains to heavily forested mountainous terrain. Unpredictable weather occurs year-round; wind, hail, and fire storms, flash flooding from the occasional torrential rain storms June through August, and unpredictably heavy snowstorms with dangerous wind chills as early as September and as late as mid-May.

Providers and nurses often care for people they know well; friends, family, and neighbors. The people who call this area home may drive up to two hours for a clinic appointment or a trip to the emergency room. People who live and work in this rural area often know who is at the clinic or hospital by observing the vehicles parked at the facility. Ambulance services and fire departments are staffed primarily by volunteers as opposed to full-time employees. The health care services are often limited by resources, expertise, and equipment. Ground and air transports to larger medical centers depend on numerous factors, such as extreme weather conditions especially during the winter. Even today, providers continue to make house calls when needed, and may drive out to meet an ambulance to allow a patient to receive treatment sooner or check in on a patient who is homebound and cannot visit the clinic.

Many of the area healthcare facilities are multi-purpose. The small hospital, long-term care facility, and clinic are physically housed in the same complex. It is increasingly common to see pharmacies, home health services, and durable medical equipment sales offices sharing space

within the hospital building. In these facilities, nurses and physicians are often generalists with additional training in geriatrics and emergency medical care. When an ambulance arrives, nurses may float from the long-term care area to cover hospitalized patients, while acute care nurses float to the emergency department to receive a patient. Ambulatory patients awaiting clinic appointments may be delayed as their provider floats to the emergency department or addresses a hospital patient arriving with unexpected complications. For many rural dwelling adults, the drive to get to the emergency room takes longer than the time it takes to be seen. Nurses working in one of the rural hospitals commented it is not uncommon for people to telephone the emergency room and provide staff warning of arrivals. The 13 rural adults interviewed were very complimentary of the care received at these rural hospitals and clinics. In fact, a couple of rural adults expressed some disappointment after the interview that no questions were asked about the state of rural healthcare, the high cost of insurance, or their ideas for solving healthcare challenges such as the number of rural people who are unable to afford insurance. Most participants appeared to speak freely, and all participants answered all questions that were asked.

Key Themes

Themes were organized based on code and code family frequency. Key themes were determined by the highest number of codes and code families, which supported each theme. Six key themes emerged from the data: 1.) Palliative care is comfort for the dying or end-of-life care; 2.) Palliative care? Never heard of it; 3.) Uncertainties about the differences between palliative care and hospice; 4.) Conflicts between theory and practice; 5.) Timing is everything; and 6.) Experience is a strong teacher. Exemplar quotes provided evidence in support of each key theme.

Palliative care is comfort for the dying or end-of-life care. Palliative Care is about providing comfort at the end-of-life. This theme occurred in 15 of the 25 interviews. Codes referencing comfort and end-of-life appeared 89 times throughout the interviews, with the heaviest concentration or density in the rural nurse group. Providing comfort at the end-of-life emerged as the predominant theme of the providers ($n = 5$) and nurses ($n = 7$). Rural nurses often float between the emergency department and the hospital, or between the long-term care facility and the hospital. In some facilities, nurses may split their time between multiple areas. Six nurses who talked about palliative care as end-of-life care were asked for a personal definition of palliative care. The following are three exemplar quotes provided by rural nurses:

“I would define that [palliative care] as end-of-life care. You’re basically just keeping that person comfortable for end-of-life.” – RN01

“Providing nursing and medical care to a person who is terminally ill. That medical and nursing care concentrate on providing comfort to the person who is in the process of dying.” – RN06

“...all the interventions are concentrated on providing the comfort, not the curing.” – RN06

The one nurse who did not define palliative care as end-of-life care was uncertain about the definition of palliative care and thought it was providing nursing care of the body immediately after death and prior to the mortuary coming to pick up the body.

Apart from nurses, rural providers also defined palliative care as providing comfort at the end-of-life ($n = 4$). The interviewed providers work at stand-alone primary care clinics across

small towns and rural hospitals with primary care clinics and long-term care facilities attached to the hospital.

“I think it means keeping people comfortable at the end of their life.” – RP05

“Helping a person with their end-stage living as best we can.” – RP04

One provider, who practices in multiple settings throughout the day and has made home visits to offer palliation to rural patients at the end-of-life, termed this wide variation in practice as a specialization: “rural medicine”. This provider, had received some informal mentoring from a palliative care physician, and supported having earlier conversations with patients.

“Palliative care is not necessarily when end-of-life is expected acutely, end-of-life will probably come in the near future. It can start in a primary care provider’s office and continue up through specialists.” This provider discussed having conversations with clinic patients in their 40s, 50s, and 60s even before palliative care concerns are identified.” – RP03

Six of the 13 rural dwelling adults who were interviewed view palliative care as keeping someone comfortable who was at the end-of-life.

“My definition is probably going to have to be about end-of-life...letting a patient die as comfortably as possible.” – RD04

“To make it so they are not in pain; making them comfortable until they die.” – RD07

Palliative Care? Never heard of it. The majority of interviewed rural dwelling respondents were adults who are uncertain what palliative care may be and what it entails. As many as seven rural dwelling adults reported they were unfamiliar with the term palliative care. Meanwhile, four participants speculated about what palliative care may be.

“Pail-ee-uh-tiv? The care I would like? I really don’t know. [Laughs]” – RD05

“I’m not exactly sure of the definition – it is one of a circle of cares that you can receive when you are sick or injured...Curative? I would hope so, but I really don’t know.” –

RD02

Despite the ambivalence surrounding palliative care, all 13 rural dwelling adults stated they were familiar with hospice care and provided an accurate definition, as did the 12 rural providers and nurses.

Uncertainties about the differences between palliative care and hospice. Four nurses were uncertain about the differences between palliative care and hospice.

“I’m not really sure of the difference between hospice and palliative care.” – RN05

“They’re different- there is a fine line- but I’m not sure.” – RN04

“Different protocols and different [governing] body?” – RN06

One provider and two nurses described no differences between hospice and palliative care.

“One is the same as the other to me.” – RN01

“I think that hospice provides palliative care, but you don’t necessarily have to be in hospice to receive that because we do that here at our hospital.” – RP05

Conflicts between theory and practice. In theory, four of the five rural providers correctly identified that palliative care can be provided for a longer period; they mostly agreed that palliative care could be delivered concurrently with usual treatment. However, conflicting information was evidenced throughout the interviews, suggesting that actual practices might be different.

“Treating the whole person. Any chronic issue that is debilitating.” – RP02 [In response

to interviewer's request to provide a personal definition of palliative care.]

Contrasting statement:

“You know, sometimes you start the palliative care and then people do tend to do better and you are still trying- and they are not wanting to stop treatments.” – RP02

“Is it reimbursable? There's a medical-legal issue of, an insurance issue, of reimbursement of what services are available to somebody. Can you do it? Certainly. Is there benefit to it? ...Our society has evolved technically much more quickly than it has societally...we can maintain people alive for much longer than they have a quality of life. We're able to sustain people much longer, but to what end.” – RP01

Contrasting statement:

“Palliative care, to me, is providing comfort to somebody instead of curative measures.”
– RP01

Timing is everything. Most rural providers defined palliative care as occurring over a longer period when compared to hospice care. When nurses were asked about the timing of palliative care, most of them talked about the timing of palliative care as restrictive, such as the Medicare hospice certification requirements of a life expectancy of six months or less, or with the finality of life.

“When they have come to the decision that is what they want- end-of-life less than six months.” – RN03

“I think at the point that you feel death is imminent from a disease process.” – RN05

“Uncertain whether it is three or six months that we do not expect the person to recover-

and all the interventions are concentrated on providing the comfort, not the curing.” –

RN06

“I think when end-of-life is ‘there’.” – RN07

Rural providers described the timing of palliative care differently based on the individual patients presenting to them. They mostly described palliative care as occurring over a longer period than hospice care.

“Palliative care, to me, is providing comfort to somebody instead of curative measures. If they choose palliation versus curative interventions...maybe six months, three months, a year...but it is an individual decision.” - RP01

“Well, everybody is an individual, so there is no real set time.” – RP04

“Palliative care is something that we should discuss with patients before they are at that end-stage. Guidelines- when death is expected in the next two years. If you are looking at CMS and Medicare guidelines- it can be very specific. I just want the patient taken care of.” – RP03

Experience is a strong teacher. Interviews with rural providers, nurses, and adults revealed a common underlying thread, *experience*. Each respondent cited examples to support their thoughts and most of them were based on personal experiences. Rural dwelling adults also shared memories of family members who received hospice care at home, describing palliative care as hospice care.

“I would define it [palliative care] as treatment during a stage of life when there aren’t any avenues for complete change to the situation, and you are making that person

comfortable for as long as possible – until another factor takes over and they pass away.” – RD03

Later in the same interview with RD03, *“I had a sister- 20 years ago- who we had hospice care for...she had ovarian cancer. It was a lifesaver, a very positive experience.”*

Nearly every participant talked about a family member suffering from a serious condition, and many of these examples included stories of hospice. Additionally, a rural provider, RP03 made mention of a mentorship completed with a palliative medicine physician. RP03 then defined the timing of palliative care in terms of palliative medicine, life expectancy less than two years. One rural nurse, RN06, described palliative care training completed as part of the nursing academic preparation. RN06 described a short clinical rotation in a large hospice organization, and subsequently described palliative care as providing comfort at the end-of-life. RN06 described the differences between hospice and palliative care as having different governing structures and policies, albeit sharing similarities in the end-of-life care provided. Based on these examples, it can be surmised that experience is a strong teacher which does influence perceptions.

Quantitative Results

The internal consistency of the PCKT was found to be acceptable ($\alpha = .77$; Tavalok & Dennick, 2011).

Sample characteristics. Most participants were female, married, long-time rural residents who were nurses employed in a hospital setting for more than 35 hours a week. Additional sample characteristics are outlined in Tables 1 and 2.

PCKT overall scores. Percentages of correct responses to PCKT questions are reported in Table 3. Question 3 and question 15 had the highest number of correct responses (94%, $n = 48$ for each). On the other hand, question 7 and question 13 had the lowest percentages of correct responses (4%, $n = 2$; 10%, $n = 5$). Of 20 possible points, the mean PCKT total score for the entire sample ($n = 51$) was 10.73 ($SD 2.93$). According to the PCKT authors, questions 12 and 14 evaluated knowledge that was no longer included in current practice. Thus, the mean PCKT total score calculated without Questions 12 and 14 was lower for the entire sample ($n = 51$) $M = 9.59$ ($SD 2.73$). After review and discussion of the study aims, it was decided to continue the analysis using the data based on the PCKT instrument as originally designed with all 20 questions.

Table 3
Percentages of Correct Responses to PCKT Questions

PCKT Question	Providers	Nurses	Total
	$n = 7$	$n = 44$	$n = 51$
	n (%)	n (%)	n (%)
1. Palliative care should only be provided for patients who have no curative treatment available.	5 (71)	35 (79)	40 (78)
2. Palliative care should not be provided along with anti-cancer treatments.	7 (100)	33 (75)	40 (78)
3. One of the goals of pain management is to get a good night's sleep.	7 (100)	41 (93)	48 (94)
4. When cancer pain is mild, pentazocine should be used more than an opioid.	1 (14)	11 (25)	12 (24)
5. When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used.	7 (100)	26 (59)	33 (65)
6. The effects of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used.	1 (14)	10 (23)	11 (22)
7. Long-term use of opioids can induce addiction.	0 (0)	2 (5)	2 (4)
8. Use of opioids does not influence survival time.	2 (29)	22 (50)	24 (47)
9. Morphine should be used to relieve dyspnea in cancer patients.	6 (86)	29 (66)	35 (69)
10. When opioids are taken on a regular basis, respiratory depression will be common.	6 (86)	17 (39)	23 (45)
11. Oxygen saturation levels are correlated with dyspnea.	5 (71)	22 (50)	27 (53)
12. Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.	6 (86)	34 (77)	40 (78)
13. During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient comfort.	2 (29)	3 (7)	5 (10)
14. Benzodiazepines should be effective for controlling delirium.	3 (43)	15 (34)	18 (35)
15. Some dying patients will require continuous sedation to relieve suffering.	7 (100)	41 (93)	48 (94)
16. Morphine is often a cause of delirium in terminally ill cancer patients.	5 (71)	18 (41)	23 (45)
17. At terminal stages of cancer, higher calorie intake is needed compared to early stages.	4 (57)	27 (61)	31 (61)
18. There is no route except central venous for patients unable to maintain a peripheral intravenous route.	5 (71)	34 (77)	39 (77)
19. Steroids should improve appetite among patients with advanced cancer.	2 (29)	14 (32)	16 (31)
20. Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	5 (71)	27 (61)	32 (63)

Note. Bold indicates lowest percentage of correct answers.

Comparing PCKT scores between groups. PCKT total score and domain scores are illustrated in Table 4. A Mann-Whitney *U* test was run to determine any differences in PCKT total scores between rural providers ($n = 7$) and rural nurses ($n = 44$). Distributions of the PCKT total scores for rural providers and rural nurses were dissimilar, as assessed by visual inspection. PCKT total scores for rural providers (mean rank = 35.21) and nurses (mean rank = 24.53) were not statistically different ($U = 89.5, z = -1.78, p = .075$). A Mann-Whitney *U* test was run for each of the five domains to determine the presence of significant differences in PCKT domain scores between rural providers and rural nurses. After the visual inspection of the distributions of the five PCKT domain scores, all were found to be dissimilar. For the Dyspnea domain, rural providers (mean rank = 36.43) scored statistically significantly higher than the rural nurses (mean rank = 24.34, $U = 81, z = -2.084, p = .037, d = 0.51$). The scores of the four remaining PCKT domains were not statistically significantly different (Philosophy [mean rank = 27.93, 25.69, $U = 140.5, z = -.445, p = .656$], Pain [mean rank = 28.14, 25.66, $U = 139, z = -.430, p = .667$], Psychological Problems [mean rank = 34.50, 24.65, $U = 94.5, z = -1.751, p = .08$], and Gastrointestinal Problems [mean rank = 26.00, 26.00, $U = 154, z = 0, p = 1$]).

Table 4.
PCKT Total Score and Domain Scores by Rural Group

	Providers $n = 7$ $M(SD)$	Nurses $n = 44$ $M(SD)$	Total $n = 51$ $M(SD)$
PCKT Total Score	12.29 (2.69)	10.48 (2.91)	10.73 (2.93)
Domains			
Philosophy	1.71 (0.49)	1.55 (0.70)	1.57 (0.67)
Pain	2.57 (0.54)	2.55 (1.21)	2.55 (1.14)
Dyspnea*	3.29 (0.76)	2.32 (1.20)	2.45 (1.19)

Psychiatric Problems	2.43 (0.98)	1.75 (0.78)	1.84 (0.83)
Gastrointestinal Problems	2.29 (1.25)	2.32 (1.05)	2.31 (1.07)

* $p < .05$

Palliative care training. Eighty-two percent of the providers and nurses ($n = 41$) responded in the negative when asked if they had completed any form of palliative care training. Nine providers and nurses (18%) reported completing some form of palliative care training, while five (56%) reported completing a continuing education course or seminar. Providers and nurses who had completed some form of palliative care training ($n = 9$) scored higher on the PCKT Total Score ($M 12$, $SD 12.25$) than those who did not ($n = 42$, $M 52.26$, $SD 14.87$). However, the difference in PCKT Total Scores between those who completed some form of palliative care training and those who had not were nonsignificant ($p = .198$).

Categorical Principal Component Analysis (CATPCA). The model accounted for 34% ($d = 0.90$) of the variance in the optimally scaled matrix of 20 items, comprising of two constructs; both constructs had eigen values greater than 3. Constructs with eigen values of greater than 1.00 are considered appropriate for consideration (Meyers et al., 2013). The first construct, Maturity, comprised 18% ($d = 0.75$) of the total variance within the model. Meanwhile the second construct, Rural Investment, accounted for 16% ($d = 0.73$) of the total variance. The following components were included in Maturity (correlations in parenthesis): Age (.69), Position (.64), Experience (.62), Education (.60), Total Years Lived Rurally (.59). On a similar note, the following components were included in Rural Investment: Specialization (.85), Primary Practice Setting (.70), Years Lived in the Current Area (.60).

Power. G*Power Version 3.1.9.2 was used to conduct the a priori and post hoc power analyses. A post hoc power analysis was calculated using the Means: Wilcoxon-Mann-Whitney test (two groups) to compute the actual achieved power with the Rural Provider group ($n = 7$) and the Rural Nurse group ($n = 44$). The power was determined to be 0.22, critical $t = 2.01$, $df 47.70$. In support of the exploratory approach of this study, a post hoc power analysis using the Means: Wilcoxon-signed rank test (one sample case) was calculated using the obtained sample ($n = 51$). The actual power was calculated to be 0.96, critical $t = 1.20$, $df 46.70$, $d = 0.50$.

Discussion

The quality of the study was maintained by using two researchers in the analysis process, critical debate and discussion, and a statistical consultant. The research methods, analyses, results, and conclusions were presented, examined, and discussed with a panel of four independent, experienced researchers prior to submitting this manuscript for publication.

The purpose of this mixed methods study was to explore the perceptions of palliative care among rural providers, nurses and adults. The primary aim was to explore and compare the palliative care perceptions of rural dwelling providers, nurses, and adults. The secondary aim was to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses practicing in rural areas. Both aims were accomplished by this study.

The decision to include all 20 PCKT questions was based on the specific aims and the exploratory nature of this study. After excluding the two questions, total PCKT scores for the sample ($n = 51$) were found to be lower. The low PCKT scores obtained by rural providers and rural nurses, when combined with the key themes that palliative care is perceived as end-of-life care, makes it alarmingly clear that significant changes are needed to improve the quality of

provider and nurse academic preparation and continuing education related to palliative care. These findings were strengthened using the convergent parallel design. One rural nurse interviewed for this study, RN06, talked about palliative care as end-of-life care, which was reinforced by the wonderful clinical experience of RN06 in a hospice setting.

The findings of this study are reinforced by previously published studies, which suggested that providers and nurses are confused about the broader applications of palliative care (Golla, Galusko, Pfaff, & Voltz, 2014; Weil et al., 2015), and that they largely perceive palliative care to be synonymous with end-of-life or hospice care (Golla et al., 2014; Kavalieratos et al., 2014; LeBlanc et al., 2015; Weil et al., 2015). The differences between understanding the theoretical value of broad-based palliative care and contradicting statements made during the interviews raise important questions about the influence of reimbursements and experiences when combined with poor palliative care knowledge, as measured by the PCKT (providers 61.5% correct, nurses 52.4% correct). Overall total PCKT scores, which indicate poor knowledge about palliative care in this study, are supported by previously published studies that included providers from rural areas (Kavalieratos et al., 2014; LeBlanc et al., 2015). The perceptions of rural adults in this study range from having no idea about what palliative care is, to perceptions that palliative care is hospice care or end-of-life care. Finding from this study related to rural adults are supported by a recent study of community dwelling adults ($n = 301$) which found relatively poor palliative care knowledge among adults in the U.S. (Kozlov, McDarby, Reid, & Carpenter, 2017).

The exploratory CATPCA identified two constructs, Maturity and Rural Investment, which assume meaningful significance for providers and nurses practicing in rural areas. Many of these providers and nurses are living and working right where they want to be. Although exploratory,

the constructs of Maturity and Rural Investment have been supported by existing research. Providers who practice in rural areas are more likely to be from rural areas (Lindsay, 2007). The sample characteristics of participants in both components of this study support the viewpoint that providers and nurses who practice in the studied geographic area are experienced and have lived and practiced in rural areas for a considerable time. This supports the construct of Maturity and Rural Investment. Rural nurses are generalists with expertise in many areas (Lee & McDonagh, 2013; Scharff, 2013), are well-known, and are involved in many aspects of life in the rural area where this study was conducted, which lends additional support to the construct of Rural Investment.

Limitations

As a study of two independent samples, this study is significantly underpowered. Originally, the *a priori* power analysis was calculated using a two-tailed *t*-test, difference between two independent means (two groups). Based on the level of the data and non-experimental design, a Wilcoxon-Mann-Whitney test (two groups), should have been ideally used to determine the sample size. However, the desired sample size needed in each group increased by only three. A post hoc power analysis using the obtained sample (one group) calculated the power to be 0.96 with a medium effect size ($d = .50$). Threats relating to small sample size and low power are reduced by the mixed methods design (Creswell, 2014). Similarly, the expansive geographic area of this study posed some challenges. For example, a few face-to-face interviews were extremely short and theoretical saturation was not achieved in the provider group due to recruitment difficulties and a lack of additional time. Some rural health clinics were open for very limited hours and were staffed by providers and nurses who also worked at other facilities. Furthermore,

the 19 healthcare facilities initially identified may have given an inaccurate idea of the number of providers and nurses within the study area. Visiting each organization and providing sufficient survey packets for the employed providers and nurses ($n = 99$) provided a better assessment of the study population. The geographic area of this study is sparsely populated, and several organizations employed small staffs with only a provider or two, in addition to a nurse or medical assistant. Therefore, despite its limitations, the small sample ($n = 51$) is a reasonable representation of the population. Moreover, the mean PCKT total scores were slightly higher, yet comparable, to the total PCKT scores reported for a sample of nurses ($n = 35$) in rural Kentucky (Evans, 2016).

Conclusions

Considering the results of this small-scale study, coupled with the evidence presented by existing research, it can be concluded that the misperceptions and poor knowledge related to palliative care likely prevent the broader application of palliative care in the rural and highly rural areas where this study was conducted. Rural and urban health care disparities continue to widen, and the number of rural dwelling adults impacted by serious chronic conditions continues to grow at a worrying pace. Concurrent palliative care, when offered as a vital component of comprehensive primary care in rural areas, may provide the best opportunity for rural adults to remain active and age in place. However, the perceptions that palliative care is end-of-life care may serve as a significant barrier for providers and nurses practicing in rural areas, as well as rural dwelling adults who could benefit from concurrent palliative care. Future initiatives may include: redesigning medical and nursing education to include broad-based or concurrent palliative care; educating people in rural areas about the broad scope of palliative care; and working with both policy makers and payers on palliative care reimbursement. Indisputably, additional research is

needed on rural populations. To that end, future studies may include: the role of concurrent palliative care within rural primary care, the way experiences influence practice in rural areas, and the economic impacts of broad-based palliative care in rural areas. Additional rural research opportunities exist to include certified and unlicensed staff that faithfully support rural health care, but were not included in this study, such as medical assistants, nursing assistants, emergency medical technicians, and first responders.

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