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

by
Tamara L. Tasseff

A dissertation
submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy in the Department of Nursing
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To the Graduate Faculty:

The members of the committee appointed to examine the dissertation of TAMARA L. TASSEFF find it satisfactory and recommend that it be accepted.

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RE: regarding study number IRB-FY2018-38 : New

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I have reviewed your request for expedited approval of the new study listed above. This is to confirm that I have approved your application.

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Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

Dedication

“Trust in the Lord with all your heart, and do not lean on your own understanding. In all your ways acknowledge him, and he will make straight your paths” (Proverbs 3:5-6, English Standard Version).

This three-manuscript option dissertation, first and foremost, is dedicated to Jesus Christ, my Lord and Savior. For without his grace and intercession, I would have surely missed the most important parts of life and the deeper learning that occurred during this experience. *Here am I, Lord.* Now use me and this wonderful education to do your will and not my own.

Second, the third manuscript is dedicated to my husband, Aaron Zane Tasseff, United States Navy, retired, who has unselfishly supported me in more ways than I can count. Thank you for your unconditional love and for being a continued blessing in my life; thank you for your noble service and sacrifices to our Nation and here at home; and thank you for being the man who shows me every day why this research is absolutely necessary and long overdue.

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Last but certainly not least, I would like to express my sincere gratitude to my children, grandchildren, parents and friends. Your caring, prayers and encouragement mean more to me than you will ever know. *If riches are measured in those who love and care for us, then I am indeed a very wealthy woman.*

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Abstract

Exploring Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, Adults, and Veterans Using a Convergent Parallel Design Dissertation Abstract—Idaho State University (2018)

This three-manuscript dissertation reports the mixed methods dissertation research conducted to explore the palliative care perceptions of rural dwelling providers, nurses, adults, and veterans using a convergent parallel design. The secondary research aim was to explore the relationship between knowledge and perceptions of palliative care held by rural providers and nurses. The results are reported in three manuscripts; an integrative literature review, a report of the full mixed methods study, and a qualitative account of the rural veteran participants. Following institutional review board approval, 25 rural participants (providers, $n = 5$; nurses, $n = 7$; adults, $n = 7$; and veterans, $n = 6$) from a geographically defined area of over 8,500 square miles completed audio-recorded, face-to-face, semi-structured interviews; and 51 participants (providers, $n = 7$; nurses, $n = 41$) from 19 organizations within the study area completed the 20-item Palliative Care Knowledge Test (PCKT). Both samples answered 13 demographic questions. Veterans answered an additional seven questions related to their service. Qualitative data was analyzed using thematic analysis. Quantitative analysis was performed using SPSS, Version 23. Qualitative and quantitative data were analyzed separately before merging and comparing in the final analysis. Six themes were identified: Palliative care is comfort for the dying or end-of-life care; Palliative care? Never heard of it; Uncertainties about the differences between palliative care and hospice; Conflicts between theory and practice; Timing is everything; and Experience is a strong teacher. In contrast to the other groups, none of the rural

veterans associated palliative care with hospice care, and none of the rural veterans were able to define palliative care. PCKT total scores for the sample of providers and nurses ($n = 51$) was 10.73 ($SD\ 2.93$) suggesting relatively poor palliative care knowledge. Two constructs, Maturity and Rural Investment, were identified. Providers and nurses in rural areas are experienced, have lived and practiced in rural areas for considerable time supporting the constructs of Maturity and Rural Investment. Broad-based palliative care education is needed for rural adults and veterans and the providers and nurses who provide care in rural areas.

Keywords: Rural, palliative care, hospice care, veterans, perceptions

Word count: 342

CHAPTER 1: Introduction

Overview of Three Manuscripts

Three manuscripts were prepared to share the findings of this mixed methods research study. A convergent parallel design was used to explore and compare perceptions of palliative care held by providers and nurses who practice in rural areas, rural dwelling adults, and rural veterans. The first manuscript, an integrative literature review, provides the background evidence supporting the gap in the literature and the need for this dissertation research study. The second manuscript presents the data and results of this mixed methods study exploring the perceptions of palliative care among rural dwelling providers, nurses, and adults. The third manuscript presents a qualitative exploration of the palliative care perceptions among the six rural dwelling veterans who participated in the qualitative component of the larger mixed methods study.

This chapter begins with a background for the research followed by a brief introduction of each of the three manuscripts. The introduction of each manuscript includes the rationale for journal selection and an explanation of the manuscript preparation, including the style or standards for preparation requested by each of the selected peer-reviewed journals. Each manuscript, as presented in this chapter, was formatted according to the selected journal's submission requirements. A discussion related to the three manuscripts is found in the fifth chapter.

Background

Palliative care has the potential to help improve the lives of people suffering from serious chronic conditions, such as cancer, multiple sclerosis, rheumatoid arthritis, heart failure, dementia, and diabetes (World Health Organization, 2016). Palliative care can be delivered concurrently with usual or curative treatment at any point in the disease trajectory (Hargadon,

Tran, Stephen, & Homler, 2017; Meier & Bowman, 2017). Globally, less than 15 percent of the people who could benefit from palliative care receive it (World Health Organization, 2017).

Many of these people live in rural areas.

In the United States, 47 million people live rurally and occupy 72 percent of the land (Cromartie, 2015). Rural dwelling adults, when compared with their urban dwelling counterparts, are older, have smaller incomes, are less healthy, and have reduced access to health care services (Bolin et al., 2015). They serve in the military at disproportionately higher rates than their urban counterparts, 19 percent compared with 16 percent (United States Department of Agriculture Economic Research Service, 2013).

Veterans are important subculture of the rural dwelling population. Nationally, eleven percent of veterans live in rural areas and account for roughly 30 percent of the larger veteran population. However, in the geographic area of this study, veterans account for 14 percent of the rural population (United States Census Bureau, n.d.). On average, they are older and more disabled than the larger rural population, experience greater healthcare-related disparities than both rural dwelling non-veterans and urban dwelling veteran populations and seek healthcare from rural providers and VA providers. (Tasseff & Tavernier, 2018). Despite an older and sicker rural population, fewer physicians and nurses work in rural areas (Bolin et al., 2015).

By 2020, 56 percent of rural veterans will be age 65 or older (Sheets & Mahoney-Gleason, 2010); by 2030, one in five Americans will be age 65 or older (Centers for Disease Control and Prevention, 2013). The incidence of chronic disease increases with age (Centers for Disease Control and Prevention, 2013), and the majority of older adults will be living with multiple chronic conditions (Gerteis et al., 2014). Chronic conditions are associated with a decreased quality of life (Centers for Disease Control and Prevention, 2013). It is well known

palliative care improves the quality of life for people living with serious chronic conditions and can be delivered concurrently (Hargadon et al., 2017; Meier & Bowman, 2017; Meier & Brawley, 2011; Murray et al., 2017). A significant barrier reported in the evidence is providers' (Golla, Galushko, Pfaff, & Voltz, 2014; Kavalieratos et al., 2014; LeBlanc et al., 2015; Weil et al., 2015) and nurses' (Golla et al., 2014; Weil et al., 2015) perceptions that palliative care is synonymous with end-of-life care. However, little is known about the perceptions of palliative care among rural providers, nurses, and adults; and less is known about the perceptions of palliative care among rural veterans.

The specific study aims of this mixed methods dissertation research study were to (1) explore and compare the perceptions and palliative care among rural dwelling providers, nurses, adults, and veterans; and (2) to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses who practice in rural areas. For the purpose of 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 nurses (LPNs) and registered nurses (RNs) who did not hold an advanced practice license.

Understanding the perceptions of palliative care among these four rural dwelling groups is a first step to transforming healthcare in rural areas. This study will provide a platform to begin discussing how to improve education and access related to palliative care and start improving the quality of life for adults and veterans living with serious chronic conditions in rural areas.

First Manuscript

The first manuscript, *An Integrative Review of Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults*, details a systematic integrative literature review.

Integrative reviews are structured, systematic reviews of qualitative, quantitative and mixed methods primary research articles (Brown, 2018). Scholarly literature reviews are the second step in the research process after formulating a research question and reveal what is known and identify gaps in the research (Polit & Beck, 2012). The first manuscript was submitted to the peer-reviewed International Journal of Palliative Nursing (IJPN). The selection of the IJPN was based on several factors, such as international readership, palliative nursing focus, and the more than 20-year history of the journal (MA Healthcare Limited, 2018). The SCImago Journal Rank (SJR) for the IJPN is 0.379 (Elsevier, 2018).

The IJPN accepts submissions of literature reviews and original research articles of 3,000 words or less; requires an abstract of 100 to 150 words; and specifies the use of certain headings in the manuscript and abstracts (MA Healthcare Limited, 2018). Three to five tables and figures may be included with submission and may be reformatted for viewing clarity. The IJPN requires manuscripts conform to the Council of Science Editors (CSE) guidelines for in-text citations and references (MA Healthcare Limited, 2018).

Second Manuscript

The second manuscript, *Exploring Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults Using a Convergent Parallel Design*, reports the mixed methods dissertation research study. This manuscript aggregates the qualitative data and sample demographics of the rural dwelling adults ($n = 7$) and veterans ($n = 6$) into one group, rural dwelling adults ($n = 13$). The second manuscript was submitted to the Online Journal of Rural Nursing and Health Care (OJRNHC). The OJRNHC provided the opportunity to report the full mixed methods study without sacrificing content or requiring submission of separate quantitative

and qualitative manuscripts. The OJRNHC has been listed in the Directory of Open Access Journals since 2005 (DOAJ, 2018)

The OJRNHC is a peer-reviewed journal focusing on rural nursing and health care and is the official journal of the Rural Nursing Organization (Rural Nurse Organization, n.d.). The OJRNHC provides a generous allowance for manuscripts reporting original research and requests that submissions include (1) an abstract of 300 words; (2) the abstract and manuscript conform to the American Psychological Association (APA) style guide with one alteration, single-spacing instead double-spacing; (4) manuscripts are 18 pages in length (single-spaced); (3) tables are single-spaced and included within the text of the manuscript; and (5) at least one author must be an RNO member (Rural Nurse Organization, n.d.). The first author of this manuscript has maintained a membership in the Rural Nurse Organization since 2016.

Third Manuscript

The third manuscript, *Exploring Perceptions of Palliative Care Among Rural Dwelling Veterans*, is focused on the rural veterans who participated in the qualitative component of the study. Veterans, in the region where this study was conducted, account for a higher percentage (14%) of the veteran population than the national average (11%), which added to the importance of reporting these results in a separate manuscript (United States Census Bureau, n.d.).

The OJRNHC was selected for submission of the third manuscript. In addition to the reasons the OJRNHC was selected for the second manuscript, the RNO hosts a biennial International Rural Nursing Conference. The first author attended the 2016 conference; presented a poster in collaboration with Dr. Tavernier; and attended an excellent presentation about rural veterans while at the conference. Actively participating in professional organizations and submitting manuscripts to the journals associated with professional organizations, such as

the RNO, are important scholarly activities, allowing nurse researchers to add evidence to the body of nursing knowledge, which informs evidence-based practice.

References

- Beatty, S. (2016, August 2). Journal metrics in Scopus: SCImago Journal Rank (SJR) |. Retrieved March 10, 2018, from <https://blog.scopus.com/posts/journal-metrics-in-scopus-scimago-journal-rank-sjr>
- Bolin, J. N., Bellamy, G. R., Ferdinand, A. O., Vuong, A. M., Kash, B. A., Schulze, A., & Helduser, J. W. (2015). Rural Healthy People 2020: New decade, same challenges. *The Journal of Rural Health, 31*(3), 326–333. <https://doi.org/10.1111/jrh.12116>
- Brown, S. J. (2018). *Evidence-based nursing: The research-practice connection* (4th ed.). Burlington, MA: Jones and Bartlett Learning.
- Centers for Disease Control and Prevention. (2013). *The state of aging and health in America 2013* (p. 60). US Department of Health and Human Services. Retrieved from <http://www.cdc.gov/aging/help/dph-aging/state-aging-health.html>
- Cromartie, J. (2015, June 15). USDA Economic Research Service - Population & Migration. Retrieved November 28, 2015, from <http://www.ers.usda.gov/topics/rural-economy-population/population-migration.aspx>
- DOAJ. (2018). DOAJ Directory of Open Access Journals. Retrieved March 10, 2018, from <https://doaj.org>
- Elsevier. (2018). Sources. Retrieved from <https://www.scopus.com/>
- Gerteis, J., Izrael, D., Deitz, D., LeRoy, L., Ricciardi, R., Miller, T., & Basu, J. (2014). *Multiple chronic conditions chartbook* (No. AHRQ Q14-0038) (p. 52). Rockerville, MD: Agency for Healthcare Research and Quality. Retrieved from <http://www.cdc.gov/chronicdisease/overview/>

- Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2014). Multiple sclerosis and palliative care - perceptions of severely affected multiple sclerosis patients and their health professionals: a qualitative study. *BMC Palliative Care*, 13(1), 1–23. <https://doi.org/10.1186/1472-684X-13-11>
- Hargadon, A., Tran, Q., Stephen, K., & Homler, H. (2017). A Trial of concurrent care: Shedding light on the gray zone. *Journal of Palliative Medicine*, 20(2), 207–210. <https://doi.org/10.1089/jpm.2016.0279>
- Kavalieratos, D., Mitchell, E. M., Carey, T. S., Dev, S., Biddle, A. K., Reeve, B. B., ... Weinberger, M. (2014). “Not the ‘Grim Reaper Service’”: An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *Journal of the American Heart Association*, 3(1), 1–11. <https://doi.org/10.1161/JAHA.113.000544>
- LeBlanc, T. W., O'Donnell, J. D., Crowley-Matoka, M., Rabow, M. W., Smith, C. B., White, D. B., ... Schenker, Y. (2015). Perceptions of palliative care among hematologic malignancy specialists: A mixed-methods study. *Journal of Oncology Practice*, 11(2), e230–e238. <https://doi.org/10.1200/JOP.2014.001859>
- MA Healthcare Limited. (2018). International Journal of Palliative Nursing. Retrieved February 25, 2018, from <https://www.magonlinelibrary.com/journal/ijpn>
- Meier, D. E., & Bowman, B. (2017). The Changing Landscape of Palliative Care. *Generations*, 41(1), 74. Retrieved from <http://libpublic3.library.isu.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=f5h&AN=123060334&site=eds-live&scope=site>

- Meier, D. E., & Brawley, O. W. (2011). Palliative care and the quality of life. *Journal of Clinical Oncology*, 29(20), 2750–2752. Retrieved from <http://jco.ascopubs.org/content/29/20/2750.short>
- Murray, S. A., Kendall, M., Mitchell, G., Moine, S., Ambias-Novellas, J., & Boyd, K. (2017). Palliative care from diagnosis to death. *British Medical Journal*, 356: j878. <https://doi.org/10.1136/bmj.j878>
- Polit, D. F., & Beck, C. T. (2012). *Nursing research generating and assessing evidence for nursing practice* (9th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Rural Nurse Organization. (n.d.). Submissions. Retrieved February 25, 2018, from <http://rnojournl.binghamton.edu/index.php/RNO/about/submissions>
- Sheets, C. J., & Mahoney-Gleason, H. (2010). Caregiver support in the veterans health administration: caring for those who care. *Generations*, 34(2), 92–98.
- United States Census Bureau. (n.d.). County classification lookup table. United States Census Bureau. Retrieved from <https://www.census.gov/geo/reference/urban-rural.html>
- United States Department of Agriculture Economic Research Service. (2013). *Rural veterans at a glance* (No. Economic Brief Number 25) (pp. 1–6). Retrieved from www.ers.usda.gov/media/1216115/eb25.pdf
- Weil, J., Weiland, T. J., Lane, H., Jelinek, G. A., Boughey, M., Marck, C. H., & Philip, J. (2015). What’s in a name? A qualitative exploration of what is understood by “palliative care” in the emergency department. *Palliative Medicine*, 29(4), 239–301. <https://doi.org/10.1177/0269216314560801>

World Health Organization. (2016). Noncommunicable diseases and their risk factors. Retrieved September 19, 2016, from <http://www.who.int/ncds/management/palliative-care/en/>

World Health Organization. (2017, August). Palliative care fact sheet N°402. World Health Organization. Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>

CHAPTER II: Manuscript One

An Integrative Literature Review of Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults

By

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The authors have no conflicts of interest to declare.

Abstract

Title. An Integrative Literature Review of Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults

Background. Little is known about the perceptions of palliative care among rural dwelling providers, nurses, and adults. When offered as a component of primary care in rural areas, palliative care may allow rural dwelling adults with serious chronic conditions to remain productive for a longer period of time.

Aim. To explore what is currently known about the perceptions of palliative care in rural areas.

Methods. Databases were searched electronically through the Idaho State University Libraries using the EBSCOhost Research Databases. Nine articles meeting preset criteria were reviewed, synthesized, and categorized. Themes were reported narratively.

Findings. Palliative care is largely perceived as end-of-life care, mutually exclusive from curative care, or misunderstood.

Conclusion. There is limited evidence about rural perceptions of palliative care, and additional research is needed.

Keywords: palliative care, rural, perceptions, providers and nurses, rural adults

Introduction

Identified as a basic human right by the WHO, palliative care is intended to provide relief from the stress and physical, psychosocial, or spiritual suffering associated with a serious illness (WHO 2015). Although it provides relief from the distressing symptoms of a serious illness at any point in the disease trajectory, less than 15 percent of people globally suffering from a serious illness actually receive palliative care (WHO 2016). Notably, many of the people in need of palliative care live in rural areas.

In the United States (U.S.), rural dwellers account for 14 percent of the entire population and live on nearly 72 percent of the land (Cromartie 2017). Rural dwelling people tend to be self-reliant, seek health care as they deem necessary, and define health as the ability to work or be productive as opposed to the absence of disease (Long and Weinert 2013). Despite a population that is older, more economically disadvantaged, and sicker than its urban dwelling counterpart, less than 10 percent of physicians and 16 percent of nurses practice in rural areas of the country (Bolin et al. 2015).

The increasing incidence of chronic disease among the aging rural dwelling adult population will intensify the challenges facing rural healthcare. The incidence of chronic disease increases with age and reduces quality of life (Centers for Disease Control and Prevention 2013). Palliative care, when offered early and concurrently with disease-specific treatment, has been known to improve the lives of people living with serious conditions, such as heart failure (Dionne-Odom et al. 2014) and cancer (Doyle 2017).

Aim

This integrative literature review aimed to explore the literature pertaining to the perceptions of palliative care among rural dwelling providers, nurses, and adults. Concurrent

palliative care may allow rural dwelling adults living with serious chronic conditions to remain productive for a longer period of time, and possibly age in place. Understanding the perceptions of palliative care is the first step to beginning the dialogue about improving access to palliative care in rural areas.

Methods

This systematic integrative review used thematic analysis to systematically explore current literature pertaining to the perceptions of palliative care among rural dwelling providers, nurses, and adults. While systematic integrative reviews are similar to systematic reviews in process they include a review of qualitative, quantitative, and mixed methods studies as opposed to reviewing literature that reports the same research method (Brown 2018).

Identification of Studies and Inclusion Criteria

The following EBSCOhost Research Databases were electronically searched using *palliative care, rural, perceptions*: Military and Government Collection, Academic Search Complete, Alt HealthWatch, CINAHL Complete, Health Source: Nursing/Academic Edition, MEDLINE Complete. Inclusion criteria included free-of-charge, full text, primary research articles that were published in English in peer-reviewed journals between January 2013 and January 2018, with a focus on the initial perceptions of palliative care prior to receiving palliative care interventions. The literature excluded articles focused on the perceptions of palliative care among children and parents, as well as those focused solely on the perceptions of palliative care after patients were enrolled or were currently receiving this type of care.

Search Results

The search (Figure 1) resulted in discovery of 171 articles. Articles were initially reviewed by title for relevance. Articles related to the perceptions of patients and families after

the enrollment in palliative care services were excluded as most perceptions changed as a result of the experience. One hundred and forty-seven articles were eliminated, including 22 duplicates. Full-texts of the remaining 24 articles were reviewed for inclusion. Fifteen articles did not meet the inclusion criteria and were excluded primarily due to the fact that study samples did not include participants from rural areas. Five articles explicitly stated that participants from rural areas were included in the sample. Two of the five articles addressed the rural nurses' knowledge of palliative care and were included since both studies addressed the perceptions of palliative care as measured through knowledge. Perceptions are a result of what is known and experienced (Agnes and Laird 2012). An additional four articles were included as the studies were carried out in predominantly rural areas. A total of nine articles were included in the analysis to explore the perceptions of palliative care among rural dwelling providers, nurses, and adults. One mixed methods, two quantitative, and six qualitative articles were included in the analysis.

Analysis

The literature was initially divided in accordance with the research method used. The study's geographic location, sample size, rural/urban setting, and significant findings or themes were extracted (Table 1). The articles were then sorted based on groups of interest including by providers, nurses, and adults. Key themes in each of these groups were then identified. Qualitative synthesis was completed to integrate the themes across the three groups in order to formulate the primary themes that resulted from the systematic integrative literature review (Brown 2018) presented in the conclusion. Articles reporting samples with strata, such as the perceptions of palliative care held by nurses and adults, were included in the thematic analysis of both groups (Table 2). The article quality was appraised using a researcher-developed point

value which was assigned to each of the following minimum criteria, as proposed by Hannes (2011), so as to assist with scoring:

Generalizability/Transferability (1), Internal validity/Credibility (1 point), Reliability/Dependability (1 point), and Objectivity/Confirmability (1 point). Value of information (Whittemore and Knafl 2005) was added as a final criterion and assigned a value of 3 points. Articles were appraised using the sum of assigned points (maximum 7 points), with higher scores indicating a higher level of quality premised on the aim of this integrative review. No articles were excluded on the basis of quality due to the limited number of articles identified.

Findings

Provider Perceptions of Palliative Care

Researchers of four studies reported the perceptions of palliative care among providers caring for patients with multiple sclerosis in Germany (Golla et al. 2014); providers caring for patients with heart failure (Kavalieratos et al. 2014); hematologists and oncologists caring for patients with cancer in the United States (LeBlanc et al. 2015); and physicians caring for patients with advance cancer presenting to emergency departments in Australia (Weil et al. 2015). Providers accounted for a combined 126 participants in these four studies. However, physicians ($n = 120$) far outnumbered non-physician providers ($n = 6$), including nurse practitioners and physician assistants. Only one study included the perceptions of non-physician providers (Kavalieratos et al. 2014).

Most physicians were familiar with the term “palliative care” (Golla et al. 2014) and recognized its importance in improving the quality of life (Kavalieratos et al. 2014; LeBlanc et al. 2015; Weil et al. 2015). Notably, there were differences in perceptions in terms of explicit

disease processes felt to be appropriate for palliative care, the timing of commencement, and what this care encompasses.

Synonymous with end-of-life care. Researchers of four studies addressed provider perceptions of palliative care in the United States, Australia, and Germany. Providers, predominantly physicians, perceived 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). In each of the four studies, providers theoretically discussed the broader scope of palliative care. However, they described palliative care in terms of limiting criteria. Limiting criteria included: stopping treatment (LeBlanc et al. 2015), positing that palliative care goals are inconsistent with life-prolonging care (Weil et al. 2015), or restorative treatment such as physical therapy (Golla et al. 2014), and considering it appropriate when all other options have been exhausted (Kavalieratos et al. 2014). Hematologic oncologists treating cancers of the blood perceived palliative care as end-of-life care and giving up on the patient (LeBlanc et al. 2015).

When treatment ends. Four studies discussed the incompatibility of palliative care with curative or aggressive treatment. For patients with advanced cancer presenting to the emergency department (ED), providers largely perceived palliative care to be conflicting with the life-saving mission of the ED and incongruent with aggressive treatment (Weil et al. 2015). Similarly, providers treating multiple sclerosis (Golla et al. 2014), heart failure (Kavalieratos et al. 2014), and cancers of the blood (LeBlanc et al. 2015) perceived palliative care and curative or aggressive treatment to be mutually exclusive.

A source of concern. As per three studies, the providers perceived that referrals to palliative care would not be understood by patients and families. General practitioners, neurologists and providers treating multiple sclerosis (Golla et al. 2014); providers treating heart

failure (Kavalieratos et al. 2014); and hematologists treating blood cancers (LeBlanc et al. 2015) perceived that their patients would receive a palliative care referral negatively as if the provider had given up on them or quit. Furthermore, providers voiced their concerns that palliative care was inappropriate for serious illnesses with unpredictable disease trajectories, such as heart failure (Kavalieratos et al. 2014); multiple sclerosis (Golla et al. 2014); and cancers of the blood (LeBlanc et al. 2015).

More philosophical than reimbursable. Researchers of two studies described provider perceptions of palliative care as more philosophical than reimbursable; these concerns were shared by providers who lacked an understanding of concurrent palliative care (Golla et al. 2014) as well as those who utilized concurrent palliative care (LeBlanc et al. 2015).

Nurse Perceptions of Palliative Care

Researchers of five palliative care studies included participants who were nurses. Researchers of three studies reported the perceptions of palliative care among nurses caring for patients with multiple sclerosis in Germany (Golla et al. 2014); providing community-based palliative care in the Netherlands (Verschuur et al. 2014); and caring for adults with advanced cancer presenting to the emergency departments of Australia (Weil et al. 2015). Meanwhile researchers of two studies reported palliative care knowledge of rural nurses providing care for older adults in Ireland (Wilson et al. 2016) and in the United States (Evans 2016).

Uncertain. Researchers of five studies found that nurses were ambivalent about palliative care. Authors of both quantitative studies gauging the nurses' knowledge of palliative care reported high percentages of incorrect responses, marked as "unknown" (Wilson et al., 2016), or "unsure" (Evans 2016). Nurses were uncertain about the meaning and scope of palliative care (Golla et al. 2014, Weil et al. 2015); how to best communicate the palliative care

needs of patients in the community (Verschuur et al. 2014); and about the scope of palliative care for advanced cancer patients who were receiving treatments and presenting to the emergency department (Weil et al. 2015).

When treatment ends. Researchers of four studies reported that nurses perceived palliative care begins when aggressive or curative treatment ends (Golla et al. 2014; Verschuur et al. 2014; Weil et al. 2015; Wilson et al. 2016). According to the researchers of one study, 92 percent of the 61 nurses who had completed the Palliative Care Quiz for Nurses (PQCN) perceived palliative care to be incompatible with aggressive treatment (Wilson et al. 2016).

Synonymous with end of life care. Similar to the researchers' findings about physicians' perceptions of palliative care, authors of four articles reported nurses perceived palliative care to be synonymous with end-of-life care, or provided responses supporting the viewpoint that palliative care was closely associated with end-of-life care (Golla et al. 2014; Verschuur et al. 2014; Weil et al. 2015; Wilson et al. 2016).

A form of patient advocacy. According to the findings of the researchers of three studies, nurses perceived their role within palliative care as advocating for the patient in terms of early initiation into palliative care services (Verschuur et al. 2014; Weil et al. 2015) and palliating the acute symptoms of patients with advanced cancer in the emergency department setting (Weil et al. 2015). However, nurses specializing in the care of patients with multiple sclerosis discussed how palliative care could provide an additional layer of support for some patients within the nursing home setting, thereby indirectly supporting the patient advocacy role within palliative care (Golla et al. 2014).

Adult Perceptions of Palliative Care

Researchers of three studies reported the perceptions of palliative care among adults in Ireland (McIlfatrick et al. 2014); Aboriginal women with breast cancer and their carers in Australia (Dembinsky 2014); and adult patients with multiple sclerosis in Germany (Golla et al. 2014).

Death, dying, and end-of-life. Similar to the findings among providers and nurses, researchers of three studies reported that adults perceived palliative care to be synonymous with death, dying, and end-of-life care (Dembinsky 2014; Golla et al. 2014, McIlfatrick et al. 2014).

Confusing. Researchers of three studies observed adult ambiguity pertaining to palliative care. Adults were often confused about the meaning of palliative care (Dembinsky 2014; Golla et al. 2014), did not understand the differences between hospice and palliative care (Golla et al. 2014), and opined that it signified a special care for cancer patients (Golla et al. 2014; McIlfatrick et al. 2014). Adult patients with multiple sclerosis did not perceive palliative care to be appropriate for their own situations and remained confused about how palliative care could be beneficial for them (Golla et al. 2014).

Reinforced by experiences. Findings reported in the three studies suggested how adults experiencing palliative care reinforced their perceptions. Adults with multiple sclerosis treated by providers who perceived no benefits, and nurses who were confused about palliative care, perceived palliative care in a similar manner (Golla et al. 2014). Negative perceptions were reinforced for adult women with breast cancer who were referred to palliative care services far away from their homes and support systems; these perceptions included isolating, culturally insensitive, and end-of-life care (Dembinsky 2014). For adults whose only experience with

palliative care was hospice or end-of-life care, their perceptions, whether positive or negative, were likely reinforced by the experience (McIlfatrick et al. 2014).

Discussion

Palliative care is largely perceived as synonymous with end-of-life care; it is generally reserved for cases when the treatment ends. There is uncertainty and confusion surrounding the perceptions of palliative care among rural providers, nurses and adults. Providers and nurses who are concerned about how patients may perceive palliative care, or whose perceptions are the result of poor knowledge, are likely to reinforce the perceptions of the people around them, whether patients or colleagues. While it can be surmised that experiences with palliative care, whether positive or negative, serve to reinforce the perceptions, education can play a positive role in changing these perceptions (McIlfatrick et al. 2014).

This integrative literature review entails some limitations. How the inclusion/exclusion criteria were interpreted may be a limitation. More specific criteria may have further restricted the number of identified articles. Another possible limitation is one researcher extracted themes. Notably, other individuals may have identified additional themes or grouped articles differently.

Conclusions

Despite several limitations, it can be concluded that there is a significant gap in the literature related to the perceptions of palliative care among rural dwelling providers, nurses, and adults. Understanding the perceptions of palliative care is the first step towards reducing rural-urban disparities related to healthcare access in rural areas, specifically access to palliative care. By 2030, one of five people living in the United States will be aged 65 or older (Sheets & Mahoney-Gleason 2010); the majority of this population will be living with multiple chronic conditions (Gerteis et al. 2014). Palliative care offered concurrently with usual treatment, and at

an early stage of serious chronic illnesses, may help improve the quality of life of rural adults living with serious chronic conditions (Meier & Bowman 2017).

Implications for practice include broad palliative care education for rural providers and nurses, extending from academic preparation through continuing education. Importantly, palliative care education for rural adults should focus on high-level concepts such as the differences between palliative care and hospice or end-of-life care (Kozlov et al. 2017).

Recommendations for future research may include the exploration of perceptions of palliative care in rural areas by interprofessional teams, changes in medical and nursing education that put forth the broad scope of palliative care in the classroom as well as within clinical experiences, and integrative studies of concurrent palliative care throughout rural areas.

References

Agnes M, Laird C (Eds.). 2012. Webster's new world dictionary and thesaurus. New York (NY): Houghton Mifflin Harcourt Publishing.

Bolin JN, Bellamy GR, Ferdinand AO, Vuong AM, Kash BA, Schulze A, Helduser JW. 2015. Rural healthy people 2020: new decade, same challenges. *J Rural Health*. 31(3):326–33.

Brown SJ. 2018. Evidence-based nursing: the research-practice connection. 4th Ed. Burlington (MA): Jones and Bartlett Learning.

CDC (Centers for Disease Control and Prevention). 2013. The state of aging and health in America 2013 [Internet]. US Department of Health and Human Services. (US); [cited 2018 Feb 23]. Available from <http://www.cdc.gov/aging/help/dph-aging/state-aging-health.html>

Cromartie J. (2017, June 15). USDA ERS - Population & Migration [Internet]. [Updated 2017 June 15]. United States Dept of Agriculture. [cited 2018 Feb 03]. Available from <https://www.ers.usda.gov/topics/rural-economy-population/population-migration.aspx>

Dembinsky M. 2014. Exploring Yamatji perceptions and use of palliative care: an ethnographic study. *Int J Palliat Nurs.* 20(8):387–93.

Dionne-Odom JN, Kono, A, Frost J, Jackson L, Ellis D, Ahmed, A, Azuero A, Bakitas M. 2014. Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure. *J Palliat Med.* 17(9):995–1004.

Doyle C. 2017. Concurrent palliative care: recommendations from the ASCO clinical practice guideline [Internet]. ASCO; [cited 2018 Mar 11]. Available from <http://www.ascopost.com/issues/december-10-2017/concurrent-palliative-care-recommendations-from-the-asco-clinical-practice-guideline/>

Evans CA. 2016. Rural long term care nurses' knowledge of palliative care. *J Rural Nurs Health Care.* 16(2):141–167. Available from <https://doi.org/10.14574/ojrnhc.v16i2.409>

Gerteis J, Izrael, D, Deitz, D, LeRoy L, Ricciardi R., Miller T, Basu, J. 2014. Multiple chronic conditions chartbook (No. AHRQ Q14-0038) [Internet]. Rockerville, MD: Agency for Healthcare Research and Quality [cited 2018 Feb 23]. Available from <http://www.cdc.gov/chronicdisease/overview/>

Golla H, Galushko M, Pfaff H, Voltz R. 2014. Multiple sclerosis and palliative care - perceptions of severely affected multiple sclerosis patients and their health professionals: a qualitative study. *BMC Palliat Care*.13(1):1–23.

Hannes K. 2011. Chapter 4: critical appraisal of qualitative research [Internet]. Cochrane Collaboration Qualitative Methods Group; [cited 2018 Feb 23]. Available from <http://cqrmg.cochrane.org/supplemental-handbook-guidance>

Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, Abernathy AP, Weinberger M. 2014. “Not the ‘grim reaper service’”: an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc*. 3(1):1–11.

Kozlov E, McDarby M, Reid, MC, Carpenter B. 2018. Knowledge of palliative care among community-dwelling adults. *Am J Hospice and PalliatCare*. 35(4):647-51
<https://doi.org/10.1177/1049909117725725>

LeBlanc TW, O'Donnell JD, Crowley-Matoka M, Rabow MW, Smith CB, White DB, Tiver GA, Arnold RM, Schenker Y. 2015. Perceptions of palliative care among hematologic malignancy specialists: a mixed-methods study. *J Oncol Pract*.11(2):e230–8.

Lindsay S. 2007. Gender differences in rural and urban practice location among mid-level health care providers. *J Rural Health*.23(1):72–6.

Long KA, Weinert C. 2013. Rural nursing: developing the theory. In: Winters C, editor. Rural nursing concepts, theory, and practice. 4th ed. New York, NY: Springer Publishing Company. p. 1-14.

McIlfatrick S, Noble H, McCorry NK, Roulston A, Hasson F, McLaughlin D, Johnston G, Rutherford L, Payne C, Kernohan G, et al. 2014. Exploring public awareness and perceptions of palliative care: a qualitative study. *Palliat Med.*28(3):273–80.

Meier D, Bowman B. 2017. The changing landscape of palliative care. *Generations.*41(1):74-80.

Verschuur EM, Groot MM, van der Sande R. 2014. Nurses' perceptions of proactive palliative care: a Dutch focus group study. *Int J Palliat Nurs.*20(5):241–45.

Weil J, Weiland TJ, Lane H, Jelinek GA, Boughey M, Marck CH, Philip J. 2015. What's in a name? a qualitative exploration of what is understood by "palliative care" in the emergency department. *Palliat Med.*29(4):293–301.

Whittemore R, Knafl K. 2005. The integrative review: updated methodology. *J Adv Nurs.* 52(5):546–53.

WHO (World Health Organization). 2015. Palliative careN°402 [Internet]. [Updated 2017 Aug]. World Health Organization; 2015 [cited 2018 Feb 23]. Available from <http://www.who.int/mediacentre/factsheets/fs402/en/>

WHO (World Health Organization). 2016. Noncommunicable diseases and their risk factors [Internet]. World Health Organization; 2016 [cited 2018 Feb 23]. Available from: <http://www.who.int/ncds/management/palliative-care/en/>

Wilson O, Avalos G, Dowling M. 2016. Knowledge of palliative care and attitudes towards nursing the dying patient. *Br J Nurs*. 25(11):600–05.

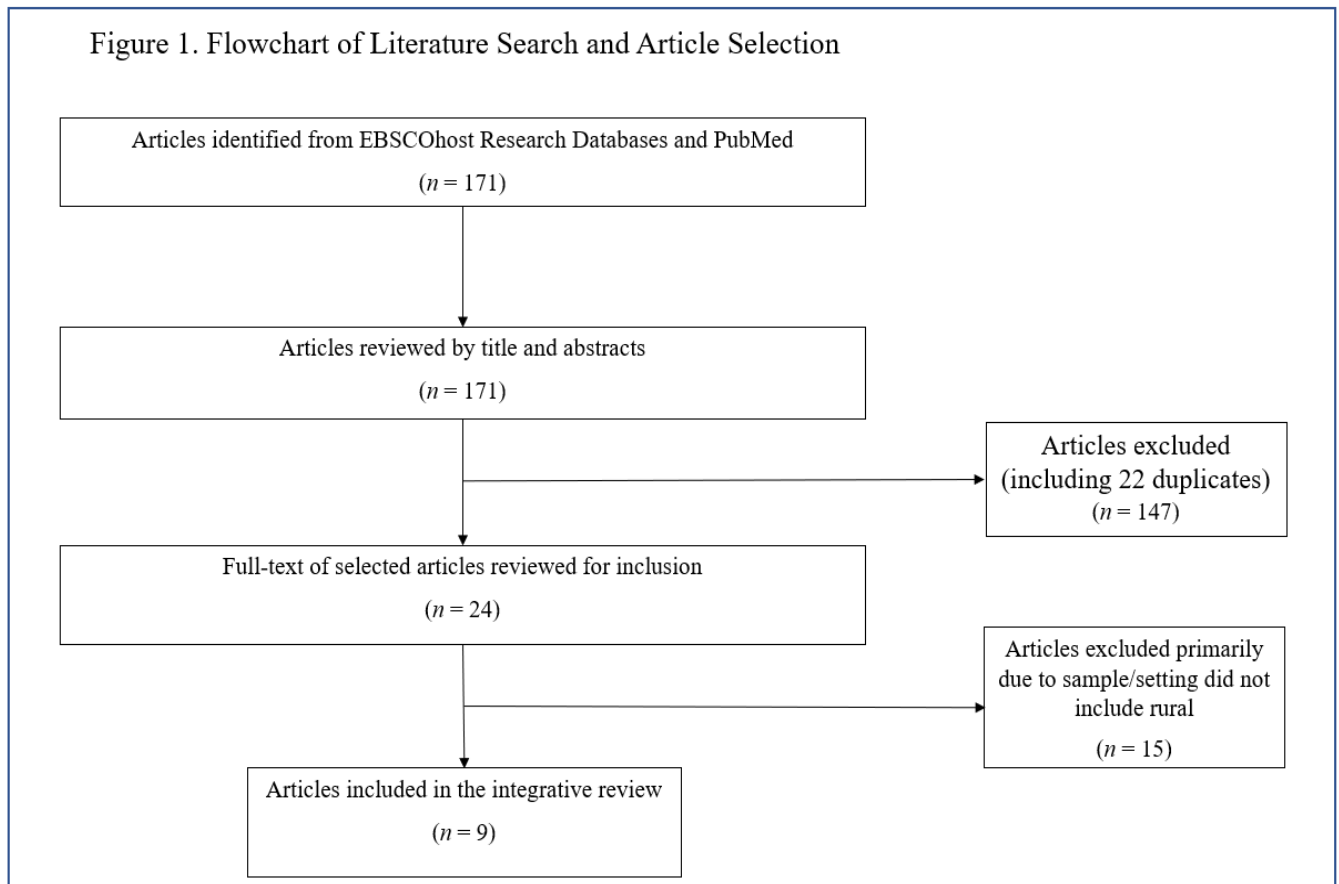
Figure 1.

Table 1: Evidence Matrix – Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults

Author/Year	Country/Sample ^a	Method	Key Findings
LeBlanc, O'Donnell, Crowley-Matoka, Rabow, Smith, White, Tiver, Arnold, & Schenker (2015)	United States Providers (n = 66)	Mixed Methods	<p>Setting: Three Academic Cancer Centers (one located in a largely rural state)</p> <p>Research purpose/aim: To understand the differences in palliative care referral practices between hematologic oncologists and oncologists who treat solid tumors related to palliative care referral practices.</p> <p>Hematologic oncologists (n = 23), oncologists (n = 43). Significant differences noted include: hematologic oncologists (n = 7, [30%]) who have never referred a patient to palliative care compared with oncologists (n = 0, [0%], $p < 0.001$); hematologic oncologists who have never referred a patient without advanced cancer to palliative care (n = 10, [43%]) compared with oncologists (n = 5, [12%], $p = 0.005$); oncologists (n = 34, [79%], $p < 0.001$) have referred patients to palliative care to assist with pain management; hematologic oncologists (n = 23 [61%]) were more likely to define palliative care as end-of-life care than oncologists (n = 6, [16%], $p < 0.001$).</p> <p><u>Strengths</u>: Mixed methods study, integration and convergence of qualitative and quantitative findings. <u>Limitations</u>: Academic medical centers (all with access to palliative care teams) may not be representative of non-academic or rural cancer centers without access to palliative care teams or services. Conclusions: Compared with solid tumor oncologists, hematologic oncologists perceive patients' symptoms are palliated as needed, palliative care is end-of-life care; and palliative care is incongruent with curative treatment. Differences may be related to practice isolation of hematologic oncologists, responsiveness of late stage blood cancers to treatments, length of elapsed time since residency. Quality: 5</p>
Evans (2016)	United States Nurses (n = 33)	Quantitative	<p>Setting: Three long term care facilities in rural Kentucky</p> <p>Research purpose/aim: To examine rural nurses' knowledge of palliative care for patients at the end-of-life in long term care facilities.</p> <p>Convenience sample of nurses ranging in age from 25 to 61 years, $M 44.5$ ($SD 9.5$), registered nurses (n = 18), licensed practical nurses (n = 15), years of practice ranged from 1 month to 28 years. The Palliative Care Knowledge Test (PCKT) was used to assess knowledge. The PCKT is a 20-item, 1-point-per-item, previously validated instrument (internal consistency 0.81) to measure palliative care knowledge, and higher scores indicate greater knowledge of palliative care.</p> <p>Important findings include: PCKT Total Score 49 percent correct, $M 9.7$ ($SD 2.60$); highest PCKT subscale score was the Pain Subscale $M 2.58$ ($SD 1.20$). No significant correlations were reported between the PCKT total score and age or years of practice. <u>Strengths</u>: Use of a previously validated instrument, sample of rural nurses, high participation (97%), rural setting. <u>Limitations</u>: Internal consistency for PCKT for this sample not reported, Significance levels reported per item between groups, however, not reported for PCKT total score or subscale scores. Conclusions: Low palliative care knowledge suggests more education is needed. Education may improve care and improve the quality of life for rural long term care residents. Quality: 5</p>
Wilson, Avalos, & Dowling (2016)	Ireland Nurses (n = 61)	Quantitative	<p>Setting: Four Private and Three State-Run Facilities in Rural County</p> <p>Research purpose/aim: Examine palliative care knowledge among nurses caring for older persons</p> <p>Nurses with significantly higher PCQN mean scores included nurses who worked in community hospitals (Mean score = 12.8, $SD 12.8$, $p < 0.001$) and nurses who completed the European</p>

Author/Year	Country/Sample ^a	Method	Key Findings
			Certificate in Essential Palliative Care (ECEPC) course (Mean score = 13.8, <i>SD</i> 2.39, $p = 0.020$). Additionally, higher PCQN scores were associated more years of nursing experience ($r = 0.295$, $p = 0.021$). Mean age 42 years (<i>SD</i> 8.8) with 51% of nurses reporting no palliative care training. <u>Strengths</u> : Use of a previously validated survey-instrument, multi-site. <u>Limitations</u> : Small sample size and cross-sectional design may limit generalizability of results. Conclusions: Nurses who completed a specific, formalized palliative care course had higher knowledge scores as did nurses who had more years of practice experience. Quality: 4
Dembinsky (2014)	Australia Total sample ($n = 28$), Adults ($n = 20$)	Qualitative	Setting: Rural/Remote Research purpose/aim: Explore perceptions and use of palliative care among Aboriginal women with breast cancer and their carers. Perceptions of palliative care are negative among Yamatji and perceived largely as end-of-life care, isolation from their family and support system, and delivered in a culturally insensitive way far from home. Although providers participated, perceptions requested were not about the providers' perceptions of palliative care. <u>Strengths</u> : Grounded theory, long term ethnography, completely rural sample, indigenous population. <u>Limitations</u> : Snowball sampling, participants may share similar perceptions; perceptions may be unique to culture. Conclusions: Experiences of culturally-insensitive palliative care delivered far from home, at the end-of-life, reinforces negative perceptions of palliative care as isolating, care for the dying. Quality: 3.5
Golla, Galushko, Pfaff, & Voltz (2014)	Germany Total Sample ($n = 38$), Adults ($n = 15$), Providers ($n = 13$), Nurses ($n = 7$)	Qualitative	Setting: Urban and rural Research purpose/aim: To investigate how people with advanced MS and their healthcare professionals perceive palliative care. Providers are physicians. Main themes related to palliative care perceptions include: uncertainty about what it is, synonymous with end-of-life care, care that they (physicians) already offer to their patients. Palliative care not defined for participants to avoid biased responses. Rural and urban comparisons not reported. <u>Strengths</u> : Stratified sample, interview guide with semi-structured questions, exemplar quotes. <u>Limitations</u> : Theoretical saturation not achieved. Rural and urban characteristics of participants not reported or compared. Conclusions: Providers, nurses, and adult patients are confused about the scope and breadth of palliative care; perceive palliative care as end-of-life care; and do not perceive value in referring patients to palliative care believing they (providers) already provide it. Quality: 6.5
Kavalieratos, Mitchell, Carey, Dev, Bodille, Reeve, Abernethy, & Morris (2014)	United States Providers ($n = 18$)	Qualitative	Setting: Academic/Nonacademic, rural, urban Research purpose/aim: To explore factors that impede palliative care referrals for heart failure patients. Providers inclusive of physicians, nurse practitioners, and physician assistants. Main themes related to palliative care: it is hospice care or associated with end-of-life, not appropriate for conditions with unpredictable trajectories, uncertain how to access. Rural urban comparisons not reported. <u>Strengths</u> : Mixed Methods, experts used in development of interview guide, case vignette and use of exemplar quotes. <u>Limitations</u> : Majority of participants from academic medical centers, all participants from one state. Conclusions: The unpredictable trajectory of heart failure combined with provider perceptions that palliative care is hospice care/end-of-life care and lack of experience with accessing palliative care impede palliative care referrals. Quality: 6

Author/Year	Country/Sample ^a	Method	Key Findings
McIlfratrick, Noble, McCorry, Roulston, Hasson, McLaughlin, Johnston, Rutherford, Payne, Kernohan, Kelly, & Craig (2014)	Ireland Adults (n = 50)	Qualitative	Setting: Telephone survey of participants in a largely rural area Research purpose/aim: To explore public perceptions of palliative care. Themes identified include: lack of knowledge about palliative care, largely associated as end-of-life care, commonly associated with cancer, media portrayal contributes to perceptions as does provider and nurse interaction. <u>Strengths</u> : large qualitative sample, coding frame informed by data, exemplar quotes. <u>Limitations</u> : Participants part of a group that provides a public voice for health and social and had previously participated in a quantitative study, possible response bias. Conclusions: Adults develop palliative care perceptions based on their personal experiences and the media; however, education can change perceptions of palliative care. Quality: 4
Verschuur, Groot, van der Sande (2014)	The Netherlands Nurses (n = 16)	Qualitative	Setting: Four hospitals and community care in a largely rural area Research purpose/aim: To explore nurses' perceptions of proactive identification of patients' palliative care needs Perceptions of palliative care nurses. This study provides validation of several other studies about delays in referrals (late referrals - patients actively dying) and the difficulties in timely communication. Perceive palliative care should start as soon as curative treatment ends supporting believe palliative care is end-of life-care. <u>Strengths</u> : Experienced moderator, multiple reviews of recordings/transcripts, initial coding by two researchers, coding discussions and consensus. <u>Limitations</u> : Sample may not be representative of larger population, use of focus groups and differences in focus group size (11 in one group, 4 in the other) may yield differing responses due to differing group dynamics. No additional demographic information was provided. Conclusions: Nurses perceive that patients need earlier referrals to palliative care while perceiving that palliative care should begin as soon as treatment ends; however, interprofessional communication and collaboration may present barriers to proactive palliative care. Quality: 4
Weil, Weiland, Lane, Jelinek, Boughey, Marck, Philip (2015)	Australia Total sample (n = 94), Providers (n = 39), Nurses (n = 47)	Qualitative	Setting: Two academic metropolitan hospitals and regional hospitals serving rural areas Research purpose/aim: To explore the understanding of palliative care among emergency department (ED) providers and nurses caring for adults with advanced cancer in the ED. Findings related to perceptions of palliative care and patients with advanced cancer presenting to the emergency department: Conflicting responses support broad utilization in theory yet describe practice limited to end-of-life, synonymous with end-of-life care, begins when treatment ends, question applicability to acute care, incongruent with aggressive treatment, uncertainty about scope. <u>Strengths</u> : Two-phase, multi-site, differing specialties and disciplines, focus groups used to inform and develop telephone interviews, multiple methods (focus groups and telephone interviews). <u>Limitations</u> : Sample characteristics limited to discipline, specialty, and region; focus groups may limit variety of responses. Conclusions: Palliative care is: not well-understood, perceived as end-of-life care; appropriate when treatment ends; conflicts with the ED mission; and is not perceived as appropriate as a concurrent treatment for people with advanced cancer undergoing treatment. Quality: 5.5

1

Table 2. Themes – Perceptions of Palliative Care Among Rural Dwelling Providers, Nurses, and Adults

Providers <i>n</i> = 4 studies (<i>n</i> = number of studies)	Nurses <i>n</i> = 5 (<i>n</i> = number of studies)	Adults <i>n</i> = 3 (<i>n</i> = number of studies)
Synonymous with end-of-life care (<i>n</i> = 4)	Uncertain (<i>n</i> = 5)	Death, dying and end-of-life (<i>n</i> = 3)
When treatment ends (<i>n</i> = 4)	When treatment ends (<i>n</i> = 4)	Confusing (<i>n</i> = 3)
A source of concern (<i>n</i> = 3)	Synonymous with end-of-life care (<i>n</i> = 4)	Reinforced by experiences (<i>n</i> = 3)
More philosophical than reimbursable (<i>n</i> = 2)	A form of patient advocacy (<i>n</i> = 3)	

CHAPTER III: Manuscript Two

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

By

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

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 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

Introduction

Palliative care improves the quality of life for patients and their families by identifying, assessing, treating and preventing the pain, stress, and symptoms, whether physical, spiritual, or psychosocial, that often accompanies a serious illness (World Health Organization, 2015). The World Health Organization 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 (World Health Organization, 2015). 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, as a whole, experience a shortage of physicians and nurses, have smaller incomes, are less healthy, and have less access to health care services 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 high deductible health plan (Leonardson, Ziller, & Coburn, 2014), which may further limit their 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, 2013), and a majority 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 (Centers for Disease Control and Prevention, 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).

Palliative care, when offered as a critical component of comprehensive primary care in rural areas, may allow rural adults with serious chronic conditions to remain active for a longer period of time 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.

In this study, 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 their limitations, thereby strengthening the analyses (Creswell, 2014). Although numerous studies have focused on the perceptions of palliative care held by healthcare professionals, such as physicians and nurses, there is little published research dedicated to providers and nurses who work in rural areas. Even fewer studies have addressed the palliative care perceptions held by rural dwelling adults.

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. The secondary aim was to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses practicing in rural areas.

Significance

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 United States. 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 around *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 Drs. 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 who experience role diffusion and lack anonymity (Lee & McDonagh, 2013). The manner in which rural dwelling adults and rural veterans 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 United States, 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 for the qualitative interviews. Eligible participants were over the age of 18 years, could speak and understand English, and lived in one of the states/counties of interest. In order 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. The interested potential participants contacted the researcher by telephone, were screened using the inclusion/exclusion criteria, and read information from the consent form. Thereafter, audio-recorded, semi-structured interviews were conducted at mutually agreed upon locations using an interview guide (see Figure 1) developed from a review of the literature and reviewed by an expert panel. All the interviews were conducted by one researcher. 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 for inclusion, and four were excluded from participating after reporting deaths of family members or close personal friends within the past six months. The final qualitative sample included 25 participants, providers (n = 5), nurses (n = 7), and adults (n = 13).

Figure 1. Semi-Structured Interview Guide

Semi-Structured Interview Guide

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

Quantitative component. An *a priori* power analysis was conducted using G*Power Version 3.1.9.2 to determine the desired total sample size ($n = 128$) based on 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). Subsequently, surveys were returned to the researcher using a prepaid, preaddressed envelope provided within the study packet.

Ethical Considerations

Ethical approval for this study was obtained from the Human Subjects Committee (study number FY2018-38) of research institution. After potential participants were provided information about the study over the telephone, the consent form was read to them as part of the screening process. Prior to the interview, signed consent was obtained. The researcher was available to answer any questions and participants were reminded that the participation was voluntary. Interviews were audio-recorded using a password protected digital recording device and transferred to a password protected, encrypted flash drive upon their completion. Files were shared among the research team using a secure and encrypted file sharing application maintained by the university. Audio files, signed consent forms with participant numbers, and any index cards with and the names and addresses of participants were stored in a locked filing cabinet in the primary researcher's home office. A Subway® gift card worth \$10 was offered to all participants as an acknowledgement of their time. No identifying information was collected as part of the survey instrument. Participants claiming remuneration were informed that the survey completion would not be anonymous, after which they provided names and mailing addresses on separate index cards returned with the completed surveys. Upon receipt, index cards were separated from the surveys; gift cards were mailed; and the index cards were stored separately in the locked filing cabinet, to which only the primary researcher had access. Study information, such as consents and index cards with names and addresses, will be stored for a period of three years before being destroyed.

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 the area of 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.

Palliative Care Knowledge Test. The PCKT (Nakazawa et al., 2009) refers to a questionnaire designed to assess the palliative care knowledge of nurses. The survey aligns with the WHO's 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), dyspnea (4 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 survey has reported an 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).

Qualitative Analysis

Qualitative analysis software, Atlas.ti, version 7.5.15 (ATLAS.ti Scientific Software Development GmbH, 2016) was used to assist with analyzing the data. The analysis of data was undertaken using thematic analysis, which supported the development of themes while staying grounded in the data. The decision to use thematic analysis as a method, following a loosely grounded theory approach to code the data into themes and subthemes, is supported. Charmaz (2006) identified that grounded theory methods have evolved from the rigid process, originally described by Strauss, and need not culminate in a finished grounded theory (Charmaz, 2006). This author defines a grounded theory approach to qualitative analysis as deploying at least two rounds of coding, preliminary and focused, while being immersed in the data. Thematic analysis as an independent method of qualitative analysis has been supported by colleagues in field of psychology (Braun & Clarke, 2006). Braun and Clarke (2006) posit that thematic analysis should be considered as a flexible method of qualitative analysis because it is not limited by the approach or research paradigm and can be performed well even by novice researchers. Multiple ways to conduct qualitative analysis exist without any one way emerging superior to another (Maxwell, 2013). The manner in which the researcher, the primary instrument used in qualitative analysis, chooses to code, combine processes, methods and approaches is primarily an individual decision predicated on what works best for the researcher (Ravich& Carl, 2016). How themes are developed is a combination of many factors, including the researcher's experience, position, underlying concepts, knowledge, and life experiences (Charmaz, 2006; Ravitch & Carl, 2016).

No less than 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, who met twice via Zoom to discuss the initial codes and preliminary findings. Subsequent interviews were coded by one researcher, adding more codes in the process. The second researcher was available throughout the process in order 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 their 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 theme.

Quantitative Analysis

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.

Analyses were performed using SPSS Version 23. Data were first reviewed for missingness. 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. Missingness 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. Notably, the themes identified in the qualitative analysis were used to inform the quantitative PCKT 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, respectively. Actual interview times ranging from six minutes 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 <i>n</i> = 5 / <i>n</i> = 7 <i>n</i> (%)		Nurses <i>n</i> = 7 / <i>n</i> = 44 <i>n</i> (%)		Adults <i>n</i> = 13 <i>n</i> (%)
	<u>Qualitative</u>	<u>Quantitative</u>	<u>Qualitative</u>	<u>Quantitative</u>	
Gender					
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>)
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	<u>Qualitative</u>	<u>Quantitative</u>	<u>Qualitative</u>	<u>Quantitative</u>	
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 the area of 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 in order to allow a patient to receive treatment sooner or check in on a patient who is homebound and cannot visit the clinic.

Many of these 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 advance warning of their arrival. 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 of them.

The primary aim of this study was to explore and compare the perceptions of palliative care held by rural dwelling providers, nurses, and adults. Themes are organized on the basis of frequency.

Key Themes

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 these 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 even made a couple of 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 a fairly 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 of time; 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. The majority of rural providers defined palliative care as occurring over a longer period of time 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 of time 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 $n = 7$	Nurses $n = 44$	Total $n = 51$
	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, $U = 139$, $z = -.430$, $p = .667$], Psychiatric 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 percent ($d = 0.90$) 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 percent ($d = 0.75$) of the total variance within the model. Meanwhile the second construct, Rural Investment, accounted for 16 percent ($d = 0.73$) 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 primary aim of this mixed methods study 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. Clinical practice guidelines addressing delirium management are available; however, research studies with higher levels of evidence are needed (Bush et al., 2014). Experts who developed the clinical practice guidelines for managing delirium in the intensive care setting provided a weak recommendation against benzodiazepine as a first-line treatment for delirium (Barr et al., 2013). Although the American Geriatrics Society strongly recommends against benzodiazepines in the geriatric surgical population, the quality of evidence remains low (National Guidelines Clearinghouse, 2015). The National Consensus Project Clinical Practice Guidelines, which address issues pertaining to palliative care, are targeted to be published in July 2018 (Sullivan, 2017). 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. Although progress has been made in improving undergraduate medical education, teaching is delivered almost exclusively by lectures and seminars, and supported mainly through hospice visits (Fitzpatrick, Heah, Patten, & Ward, 2017). Consequently, nursing students experience palliative care largely by caring for dying patients and completing hospice clinical experiences. Against this backdrop, a rural nurse interviewed for this study, RN06, talked about palliative care as end-of-life care, which was reinforced by the wonderful clinical experience RN06 experienced 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 et al., 2014; Weil et al., 2015), and that they largely perceive palliative care to be synonymous with end-of-life or hospice care (Golla, Galushko, Pfaff, & Voltz, 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 knowledge 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. This study's findings 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 United States (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 considerable time. This supports the construct of Maturity and Rural Investment. Rural nurses are generalists with expertise in many areas (Scharff, 2013), are well-known, and are involved in many aspects of life in this rural area, 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 healthcare 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 manner in which 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.

References

- Aslakson, R., Koegler, E., Moldovan, R., Shannon, K., Peters, J., Redstone, L., ... Pronovost, P. (2013). Intensive care unit nurses and palliative care: Perceptions and recommendations. *Journal of Pain & Symptom Management*, 45(2), 419–420. <https://doi.org/10.1016/j.jpainsymman.2012.10.123>
- ATLAS.ti Scientific Software Development GmbH (2016). ATLAS.ti (Version 7.5.15) [Computer software]. Berlin, Germany: ATLAS.ti Scientific Software Development GmbH
- Barr, J., Fraser, G. L., Puntillo, K., Ely, E. W., Gélinas, C., Dasta, J. F., ... American College of Critical Care Medicine. (2013). Clinical practice guidelines for the management of pain, agitation, and delirium in adult patients in the intensive care unit. *Critical Care Medicine*, 41(1), 263–306. <https://doi.org/10.1097/CCM.0b013e3182783b72>
- Bolin, J. N., Bellamy, G. R., Ferdinand, A. O., Vuong, A. M., Kash, B. A., Schulze, A., & Helduser, J. W. (2015). Rural Healthy People 2020: New decade, same challenges. *The Journal of Rural Health*, 31(3), 326–333. <https://doi.org/10.1111/jrh.12116>
- Braun, V., & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Bush, S., Bruera, E., Lawlor, P., Kanji, S., Davis, D., Agar, M., ... Pereira, J. (2014). Clinical practice guidelines for delirium management: Potential application in palliative care. *Journal of Pain and Symptom Management*, 48(2), 249–258. <https://doi.org/10.1016/j.jpainsymman.2013.09.23>
- Centers for Disease Control and Prevention. (2013). The state of aging and health in America 2013 (p. 60). US Department of Health and Human Services. Retrieved from <http://www.cdc.gov/aging/help/dph-aging/state-aging-health.html>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: SAGE Publications.
- Clark, V. L. P., & Ivankova, N. V. (2016). *Mixed methods research: A guide to the field*. Los Angeles, CA: SAGE Publications.

- Creswell, J. W. (2014). *Research design qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: SAGE.
- Dionne-Odom, J. N., Kono, A., Frost, J., Jackson, L., Ellis, D., Ahmed, A., ... Bakitas, M. (2014). Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure. *Journal of Palliative Medicine*, 17(9), 995–1004.
- Doyle, C. (2017, December 10). Concurrent palliative care: Recommendations from the ASCO clinical practice guideline. Retrieved from <http://www.ascopost.com/issues/december-10-2017/concurrent-palliative-care-recommendations-from-the-asco-clinical-practice-guideline/>
- Evans, C. A. (2016). Rural long term care nurses' knowledge of palliative care. *Online Journal of Rural Nursing & Health Care*, 16(2), 141–167. <https://doi.org/10.14574/ojrnhc.v16i2.409>
- Fitzpatrick, D., Heah, R., Patten, S., & Ward, H. (2017). Palliative care in undergraduate medical education - How far have we come? *American Journal of Hospice and Palliative Medicine*, 34(8), 762–773. <https://doi.org/10.1177/1049909116659737>
- Gerteis, J., Izrael, D., Deitz, D., LeRoy, L., Ricciardi, R., Miller, T., & Basu, J. (2014). *Multiple chronic conditions chartbook* (No. AHRQ Q14-0038) (p. 52). Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from <http://www.cdc.gov/chronicdisease/overview/>
- Glesne, C. (2016). *Becoming qualitative researchers an introduction* (5th ed.). Boston, MA: Pearson.
- Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2014). Multiple sclerosis and palliative care – perceptions of severely affected multiple sclerosis patients and their health professionals: a qualitative study. *BMC Palliative Care*, 13(1), 1–23. <https://doi.org/10.1186/1472-684X-13-11>
- Kavalieratos, D., Mitchell, E. M., Carey, T. S., Dev, S., Biddle, A. K., Reeve, B. B., ... Weinberger, M. (2014). “Not the ‘Grim Reaper Service’”: An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *Journal of the American Heart Association*, 3(1), e000544. <https://doi.org/10.1161/JAHA.113.000544>
- Kozlov, E., McDarby, M., Reid, M. C., & Carpenter, B. (2017). Knowledge of palliative care among community-dwelling adults [Epub ahead of print]. *American Journal of Hospice and Palliative Medicine*, 1–5. <https://doi.org/10.1177/1049909117725725>
- LeBlanc, T. W., O'Donnell, J. D., Crowley-Matoka, M., Rabow, M. W., Smith, C. B., White, D. B., ... Schenker, Y. (2015). Perceptions of palliative care among hematologic malignancy specialists: A mixed-methods study. *Journal of Oncology Practice*, 11(2), e230–e238. <https://doi.org/10.1200/JOP.2014.001859>

- Lee, H. J., & McDonagh, M. K. (2013). Updating the rural nursing theory base. In *Rural nursing concepts, theory, and practice* (4th ed., pp. 15–33). New York, NY: Springer Publishing Company.
- Leonardson, J. D., Ziller, E. C., & Coburn, A. F. (2014). *Rural residents more likely to be enrolled in high-deductible health plans* (Research and Policy Brief No. PB-55) (pp. 1–2). Portland, ME: University of Southern Maine, Muskie School of Public Service, Maine Rural Health Research Center. Retrieved from <http://digitalcommons.usm.maine.edu/insurance/11/>
- Lindsay, S. (2007). Gender differences in rural and urban practice location among mid-level health care providers. *Journal of Rural Health, 23*(1), 72–76.
<https://doi.org/10.1111/j.1748-0361.2006.00070.x>
- Long, K. A., & Weinert, C. (2013). Rural nursing: Developing the theory. In *Rural nursing concepts, theory, and practice* (4th ed., pp. 1–14). New York, NY: Springer Publishing Company.
- Maxwell, J. A. (2013). *Qualitative research design an interactive approach* (3rd ed.). Thousand Oaks, CA: SAGE Publications.
- Meyers, L. S., Gamst, G., & Guarino, A. J. (2013). *Applied multivariate research design and interpretation* (2nd ed.). Los Angeles, CA: SAGE Publications.
- Nakazawa, Y., Miyashita, M., Morita, T., Umeda, M., Oyagi, Y., & Ogasawara, T. (2009). The palliative care knowledge test: Reliability and validity of an instrument to measure palliative care knowledge among health professionals. *Palliative Medicine, 23*(8).
<https://doi.org/10.1177/0269216309106871>
- National Guidelines Clearinghouse. (2015). *Guideline summary: American Geriatrics Society abstracted clinical practice guideline for postoperative delirium in older adults*. Rockville, MD: Agency for Healthcare Research and Quality. Retrieved from <https://www.guideline.gov>
- O'Shea, M. F. (2014). Staff nurses' perceptions regarding palliative care for hospitalized older adults. *American Journal of Nursing, 114*(11), 26–34. Retrieved from ajnonline.com
- Polit, D. F. (2010). *Statistics and data analysis for nursing research* (2nd ed.). Upper Saddle River, NJ: Pearson Education.
- Ratcliffe, M., Burd, C., Holder, K., & Fields, A. (2016). *Defining rural at the U.S. Census Bureau* (American Community Survey and Geography Brief No. ACSGEO-1). Washington, DC: U.S. Census Bureau. Retrieved from https://www2.census.gov/geo/pdfs/reference/ua/Defining_Rural.pdf
- Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research bridging the conceptual, theoretical, and methodological*. Thousand Oaks, CA: SAGE Publications.

- Scharff, J. E. (2013). The distinctive nature and scope of rural nursing practice: Philosophical bases. In *Rural nursing concepts, theory, and practice* (4th ed., pp. 241–258). Danvers, MA: Springer Publishing Company.
- Sullivan, G. (2017, August 23). *Project overview and scope: National Consensus Project clinical practice guidelines for quality palliative care*, 4th edition (target publication July 2018).
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, 2, 53–55. <https://doi.org/10.5116/ijme.4dfb.8dfd>
- United States Census Bureau. (n.d.). *Geography urban and rural*. Retrieved from <https://www.census.gov/geo/reference/urban-rural.html>
- Vogt, W. P., Vogt, E. R., Gardner, D. C., & Haeffele, L. M. (2014). *Selecting the right analysis for your data: Quantitative, qualitative, and mixed methods*. New York, NY: The Guilford Press.
- Weil, J., Weiland, T. J., Lane, H., Jelinek, G. A., Boughey, M., Marck, C. H., & Philip, J. (2015). What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department. *Palliative Medicine*, 29(4), 239–301. <https://doi.org/10.1177/0269216314560801>
- Wilson, O., Avalos, G., & Dowling, M. (2016). Knowledge of palliative care and attitudes towards nursing the dying patient. *British Journal of Nursing*, 25(11), 600–605. <https://doi.org/10.12968/bjon.2016.25.11.600>
- World Health Organization. (2015, July). *Palliative care*. Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>

CHAPTER IV: Manuscript Three

Exploring Perceptions of Palliative Care Among Rural Dwelling Veterans

By

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Exploring Perceptions of Palliative Care
Among Rural Dwelling Veterans
Abstract

Aim. To explore the palliative care perceptions of rural dwelling veterans in a completely rural area of the United States.

Background. As a whole, rural dwelling people have reduced access to health care, including palliative care. Palliative care can effectively address the distressing physical, emotional, psychological and spiritual suffering related to either serious acute or chronic conditions; additionally, it can be delivered at the same time with usual treatment at any point in the disease trajectory to improve the quality of life for rural dwelling veterans living with serious chronic conditions. However, a significant gap exists in the research pertaining to the perceptions of palliative care among rural dwelling veterans.

Method. A qualitative study using a descriptive phenomenological approach was conducted as part of a larger mixed methods study. The setting was a geographically defined rural area encompassing over 8,500 square miles. Rural nursing theory served as the conceptual lens for this study. Audio-recorded, semi-structured, face-to-face interviews were conducted with a purposive sample of six male rural dwelling veterans using an interview guide. Subsequently, data were analyzed using a thematic analysis process.

Findings. Four themes were identified: uncertainty about palliative care; where and when; palliative care is not hospice care; and opportunities. Rural veterans were found to be unaware of the meaning of palliative care. Five of the six veterans did not perceive palliative care to be end-of-life. A unique finding, none of the rural dwelling veterans perceived palliative care to be hospice care.

Conclusions. In this study, rural veterans perceived hospice care and palliative care to be different. Veterans in this sample were unable to define palliative care and did not associate it with an improved quality of life. Therefore, broad-based palliative care education is needed for rural dwelling veterans and for healthcare professionals providing their care.

Keywords: rural veterans, palliative care, aging in place, rural nursing theory, hospice

Introduction/Background

This is an account of the qualitative component of a larger mixed methods study. The complete literature review and mixed methods study exploring and comparing the perceptions of palliative care among rural dwelling providers, nurses, and adults is described elsewhere; the qualitative component of the mixed methods study to explore the perceptions of palliative care among six male rural dwelling veterans is described here.

Palliative care has the potential to help improve the lives of people suffering serious chronic conditions, such as cancer, multiple sclerosis, rheumatoid arthritis, heart failure, dementia, and diabetes (World Health Organization, 2016). Palliative care is also beneficial in that it can be delivered at any stage of the disease course, from initial diagnosis through the end-of-life (World Health Organization, 2015). Additionally, it may be delivered concurrently with usual or curative treatment (Hargadon, Tran, Stephen, & Homler, 2017; Mor et al., 2016).

Deemed a basic human right to health care, only 14 percent of people globally receive palliative care to address the physical, psychological, emotional and spiritual suffering that often accompanies a serious illness (World Health Organization, 2016). The most basic palliative care can generally be administered by families and friends. However, the more specialized palliative care, palliative medicine, is delivered by providers who are trained to manage extremely complex symptoms. Somewhere in the middle, the potential does exist for palliative care to be delivered concurrently as a critical component of comprehensive primary care across rural areas. Notably, concurrent palliative care offers rural dwelling people the opportunity to remain active longer, experience an improved quality of life, and age in place. However, their perceptions of palliative care play an important role in transforming health care in rural areas.

The rural adult population of the United States numbers 47 million and occupies 72 percent of the land area (Cromartie, 2016). Rural dwelling adults, when compared with their urban dwelling counterparts, are older, have smaller incomes, are less healthy, and have reduced access to health care services (Bolin et al., 2015). Rural veterans account for eleven percent of the rural dwelling adult population (Holder, 2017) and roughly 30 percent of the larger veteran population (VHA Office of Rural Health, 2016). On average, they are older and more disabled than the larger rural population, experience greater healthcare-related disparities than both rural dwelling non-veterans and urban dwelling veteran populations, and seek healthcare from rural providers and VA providers. (Tasseff & Tavernier, 2018).

In the United States, hospice care is a specialized segment of palliative care directed at the end-of-life period and is often associated with Medicare specific requirements, such as certification of life expectancy of six months or less and treatment provided for comfort as opposed to cure (U.S. Centers for Medicare & Medicaid Services, n.d.). A significant barrier to palliative care may be the perceptions of palliative care as being limited to hospice or end-of-life care among physicians (LeBlanc et al., 2015) and nurses (Aslakson et al., 2013). Researchers conducting a mixed methods study of 66 oncologists at three academic cancer centers, one of which was located in a predominantly rural state in the United States (U.S.), found that the majority of the 23 hematologic oncologists who perceived palliative care to be end-of-life care

(61%) had never referred a patient to palliative care (30%), and 43 percent had never referred a patient with advanced cancer to palliative care (LeBlanc et al., 2015). Authors of a qualitative study that comprised of 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 is perceived as end-of-life care and is 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). According to the authors of a study conducted in the Netherlands, 16 nurses perceived palliative care should start as soon as the treatment ends (Verschuur, Groot, & van der Sande, 2014). Upon diagnosis with a serious health condition, patients are informed by providers about their future treatments options. To that end, nurses spend the most time with patients; however, in rural areas, nurses are often asked for advice outside of working hours (Lee & McDonagh, 2013). Experiences with both providers and nurses likely impact how adults in rural areas perceive palliative care.

The researcher of a qualitative study conducted in Australia involving 20 Aboriginal women with breast cancer and their carers reported negative perceptions of palliative care as isolating, culturally insensitive, end-of-life care and based on their experiences (Dembinsky, 2014). Correspondingly, in a qualitative study involving 50 adults conducted in a largely rural area of Northern Ireland, researchers recorded that the adults' 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 the rural adults' 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).

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 United States. It may be noted that little published research exists related to the perceptions of rural adults about palliative care, and the lack of published literature about these palliative care perceptions among the country's rural veterans indicates a significant gap in the literature. Therefore, the purpose of this research was to explore the palliative care perceptions among rural veterans.

Significance. To the best of our knowledge, the perceptions of palliative care among rural dwelling veterans have not been exclusively studied. Against this backdrop, the study provides new knowledge to (1) promote discussions about rural dwelling veterans, chronic disease, and palliative care; (2) gain insights into the perceptions of palliative care held by rural veterans; and (3) advocate for education and models of care for community and healthcare professionals that include access to culturally sensitive, concurrent palliative care.

Methods

Rural nursing theory served as the conceptual lens throughout the course of this study. Specifically, *rural dwelling people define health as the ability to do what they want to do* (Lee & McDonagh, 2013) *while remaining productive and able to work* (Long & Weinert, 2013) as opposed to perceiving health as the absence of disease. This is an important foundational concept as rural dwelling people may not be averse to living with serious chronic conditions as long as they are able to continue to do the things they want to do, including work.

Design. This was a qualitative study with a descriptive phenomenological approach conducted as part of a larger mixed methods study. Basic qualitative descriptive designs seek to describe the phenomena of interest while remaining close to the data (Sandelowski, 2000). Similar to many other qualitative studies, a specific or true structured approach was not specified in this study, thereby allowing more freedom in the methodological and conceptual decisions (Ravitch & Carl, 2016). A phenomenological approach in this study was used to explore the meaning of the perceptions of palliative care within the lived experiences of rural veterans discovering commonalities across participants (Polit & Beck, 2012).

Setting. A geographically defined area encompassing over 8,500 square miles in four counties and two western states served as the setting. The area is sparsely populated with an average of 2.5 to 5.3 people per square mile. It is classified as “mostly rural” (50% to 99.9% of the population living in rural areas) and “completed rural” (100% of the population living in rural areas) per the County Classification Lookup Table (United States Census Bureau, n.d.). Rural is defined as areas where people live that are not classified as urban or urban clusters (United States Census Bureau, n.d.).

Participants and recruitment. The recruitment phase began in September 2017 following the study’s approval granted by the Human Subjects Committee (study number FY2018-38) and continued through November 2017. Posters with tear-off-tabs containing the primary researcher’s name, telephone number and email address were placed on community message boards in grocery stores, libraries, post offices and gas stations throughout the geographic area of the study. In addition, recruitment posters were placed on rural message boards, usually located near groupings of mailboxes in some of the more remote areas. Advertisements were placed in two of the local weekly papers. Rural veterans interested in learning more about the study voluntarily contacted the researcher and were screened for inclusion by telephone. One rural veteran without a telephone expressed interest in the study after reading about it on one of the rural message boards. This veteran was screened at the location of the mailboxes and rural message board. The inclusion criteria was met if the individual was above 18 years of age, agreed to an audio-recorded interview, was a military veteran, and lived within the geographically defined area of the study. Participants were excluded if a close friend or family member had been diagnosed with a terminal illness or died in the past six months, or if the individual had received a terminal diagnosis. The consent document was read to each veteran during the screening process for consistency. Veterans meeting the inclusion criteria and desiring to participate in this study were scheduled for an interview at a mutually agreed upon location. A total of eight rural veterans responded and were screened; six of them met the inclusion criteria, provided consent and were subsequently scheduled for interviews.

Ethical considerations. Prior to the interview, each rural veteran was provided with two copies of the consent form containing information about the study. One signed consent copy was retained by the veteran, while the other one was handed over to the researcher. Each rural veteran was apprised of the voluntary nature of this study, encouraged to ask questions, and reminded that they could refuse to answer or skip any questions, and end the interview at any time. Interviews were audio-recorded using a password protected, digital recording device. Interview data was transferred to an encrypted, password protected flash drive upon the completion. Electronic files and paper consents were stored in a locked filing cabinet in the researcher's home office to which only the researcher had access. Participants were not identified by name on the audio-recordings, and the entire data was numbered to match the participant number recorded on the consent form. A Subway gift card worth \$10 was given to all participants following the interviews as an acknowledgement of their time.

Participant characteristics. Rural veteran participant characteristics are reported in Table 1. The interviews' audio-recorded portions ranged from 12 to 24 minutes. Of the six male rural veterans who participated in the face-to-face interviews, three were Air Force veterans, two were Army veterans, and one was a Navy veteran. The age of these rural veterans ranged from 53 to 76 years. Years of military service ranged from three to 21 years. The total amount of time veterans reported living rurally over the course of their lifetimes ranged from three and one half to 76 years. Similarly, the mean number of years living in the area of their current zip code or address was 21 years.

Table 1.

Rural Veterans – Participant Characteristics

	Veterans <i>n</i> (%)
Males	6 (100)
Marital Status	
Married	5 (83.3)
Divorced	1 (16.7)
Race	
White	6 (100)
Education	
HS Grad/GED	2 (33.3)
Some College	1 (16.7)
Associates	1 (16.7)
Bachelors	2 (33.3)
Employment	
< 35 hours	3 (50.0)
Not employed	3 (50.0)
Veteran Status ^a	
Non-Combat	4 (66.7)
Combat	2 (33.3)
Military Retiree	1 (16.7)
Branch of Service	
Air Force	3 (50.0)

Army	2 (33.3)
Navy	1 (16.7)
Era	
Vietnam	5 (83.3)
Desert Storm, OEF, OIF ^b	1 (16.7)
Service Connected Disability – Yes	3 (50.0)
Disability Rating	
30 Percent	1 (33.3)
70 Percent	1 (33.3)
100 Percent	1 (33.3)
<hr/>	
	<i>M (SD)</i>
Age (years)	66.8 (8.0)
Length of Service (years)	7.9 (7.1)
Rural (years) ^c	57.4 (26.9)
Current (years) ^d	21.1 (22.7)

Note: ^aTotal years, over entire life, living rurally; ^bOEF, OIF stands for Operation Enduring Freedom, Operation Iraqi Freedom; ^cTotal years of living rurally, over lifetime; ^dTotal years lived in the area of current zip code (postal code)

Data Collection. One researcher living in the area of the study conducted all six interviews. Data were collected between September and November 2017 using audio-recorded, semi-structured face-to-face interviews. A semi-structured interview guide, comprised of questions that were developed based on the published literature, was reviewed by a panel of experts experienced with qualitative research. A pilot interview was conducted with one rural veteran prior to the expert review of the semi-structured interview guide. Results from this pilot interview were neither included in the data analysis nor reported in the results. Demographic data were collected using a short questionnaire and included: gender, marital status, ethnicity, race, birth year, zip codes of home and work, total years of rural living, years lived in the area of current zip code, education, and employment. Additional demographic questions which were specific to veterans and included: combat veteran status, branch and duration of service, military retirement, service-connect disability, disability rating, and era of service. Field notes and memos were drafted using pen and paper after the interviews.

Data Analysis. Qualitative analysis software, Atlas.ti, Version 7.5.15 (ATLAS.ti Scientific Software Development GmbH, 2016) was used to assist with analyzing the data. Thematic analysis, following a loosely grounded theory approach of performing no less than three rounds of coding (Charmaz, 2006), was chosen as the method for analyzing the data.

The primary researcher listened to each audio-recording following the interview and a second time prior to beginning the preliminary (inductive) coding to identify key phrases or ideas that would be used as initial (deductive) codes during the second round of coding. Codes addressing similar thoughts or ideas were merged. After merging, the related codes were grouped together to create code families. Themes were then developed based on the frequency of the codes across these six interviews, and exemplar quotes were identified to support each theme. The audio-recordings were revisited multiple times throughout the process of analysis. The first three interviews were coded independently by two researchers. The two researchers met on two

occasions via Zoom to discuss the initial codes and preliminary findings. Theoretical saturation, the point at which collecting new data does not provide any new insights (Creswell, 2014), was reached with the sixth interview; thereafter, no further interviews were conducted.

Quality and Trustworthiness. To support quality throughout the research process, a positionality statement was drafted and shared with three more experienced researchers prior to the commencement of data collection. Positionality statements help identify biases, assist with receiving critical feedback, and present key beliefs and ideologies that shape one's research (Ravitch & Carl, 2016). The primary researcher engaged in a critical debate and discussion with a more experienced researcher throughout the process of data collection and analysis using web-conferencing capabilities. Memos and reflective journaling were used throughout the entire process. Exemplar quotes were also used to provide a representation of the rural veterans' lived experiences or realities.

Findings

Prior to being asked questions about palliative care, each rural veteran was asked for his personal definition of health or how he defined health. How rural veterans define health provides support for the study's conceptual lens that *rural dwelling people define health as the ability to do what they want to do* (Lee & McDonagh, 2013) *while remaining productive and able to work* (Long & Weinert, 2013). Five of the six veterans defined health as being able to do things, which aligns with the lens through which this study was viewed.

"Being able to do all of the normal things I've been able to do since I was 25." – RV02

"Being able to do the things you want to do in your life- whether its physical, social or whatever. Being able to do those things." - RV04

Some rural veterans were also asked what a lack of health would entail. RV04 responded, *"Inability to do the physical activities that I like to do- hiking, walking, biking, working. I like doing work [he smiles]."* Similarly, the oldest among all six veterans, RV06, who still works a couple of days each week, believes he has "fair health" right now. RV06 replied, *"I can't do now what I used to do five years ago- that's a part of health. I can't do what I used to be able to do. A year ago, I was mowing about five to six yards a week and working four to five days a week."*

Some of the rural veterans were asked if it is possible to have some degree of illness and still be healthy. This question was asked because the incidence of chronic conditions increases with aging, and chronic conditions are associated with a decreased quality of life (Centers for Disease Control and Prevention, 2013).

RV05 paused for a moment before sharing a personal example, *"I'm sure. I have a prostate condition, an enlarged prostate- and it's never been a problem, but it's there. I don't consider it hindering my health at all."* Several other veterans shared a list of chronic conditions ranging from diabetes to troublesome heart valves and severe arthritis. They stated that if they could continue doing what they want to do, they could have varying degrees of health coexisting with illness or chronic conditions. RV06 talked about fatigue and a problem he was having with his heart, *"Right now, I don't have as good of health as I had a year ago. Probably on a 1-to-100 basis, I'm a 75."*

Uncertainty about palliative care. Five of the six rural veterans did not know what palliative care was. Two veterans, RV05 and RV06, had not heard the term *palliative care* and declined to guess what it might mean. Three of the men guessed that it was probably some type

of nursing care or home care; care to provide some type of support; care for someone who needed help taking care of himself; or, care rendered for someone who had no one else to take care of him, such as care provided in a nursing home or assisted living facility.

“I have heard of palliative care, but I don’t know what it is.” – RV01

RV02 guessed that to receive palliative care, *“Somebody’s got to be in a real bad shape.”* RV04 voiced familiarity with the term palliative care and defined it as, *“I guess it’s, I don’t know, it probably isn’t the same as hospice care. Palliative care is pretty much just letting someone go [pause] to die.”* He described hospice care as occurring before palliative care and happening as a person progressed towards death.

Where and when. The intrinsic lack of clarity about the term *palliative care* made it difficult for the rural veterans to think about where and when palliative care should be delivered. Four veterans guessed about where and when it may be delivered. RV01 speculated that palliative care was possibly offered at home, *“Maybe coordinated by hospitals or clinics – almost like home health care?”* RV02 stated, *“Nursing homes? ICU? I don’t know.”* RV03 guessed, *“Nursing home – assisted living?”* After thinking about the question for a few moments, RV04 replied, *“A hospital or nursing home- maybe at home. I guess I don’t really know.”*

Palliative care is not hospice care. None of the veterans associated palliative care with hospice care. Participants were asked if palliative care and hospice care were the same. None of them perceived hospice care to be palliative care. All six rural veterans were able to define and describe hospice care fairly accurately. RV04 speculated about palliative care and thought it may occur after hospice care.

“[laughs]. I don’t know. I guess it’s – I don’t know, it’s probably not quite the same as hospice care. [Pause]. I don’t really – I think palliative care is pretty much just letting someone go [pause], to die. I think. [Pause]. And, to be comfortable.” – RV04

RV06 talked about his hospice experience decades ago when his teenage son was dying of cancer. Nearly all the veterans shared stories of family members with serious illness, such as cancer, diabetes, dementia, arthritis, and mobility issues. They were able to share personal example of hospice care.

Opportunities. Palliative care can be offered at any stage during a serious health condition. The rationale for asking the veterans about serious health conditions was to identify serious chronic conditions and bothersome symptoms for which concurrent palliative care could impart some benefits. RV01 talked about his own mobility issues, neuropathies, and diabetes, and how these ailments had significantly impacted his life:

I love to hunt and be out in the woods. Last year I did very little hunting- I think I got to hunt two days. I was afraid to leave the house, um, I’ve got a glucagon kit in my bag...it does bother me. For me, it could be life-threatening. The biggest fear is that if something happens- and I’m in the woods- drop over, go unconscious and no one finds me for three months [laughs]- and that is a great fear.

RV02 described a long course of suffering for one friend with diabetes and multiple amputations. He further spoke of another friend who battled cancer and fatigue for a year and a half. RV03 talked about his own mobility issues, the challenges of multiple broken bones and arthritis, and his desire to continue living rurally despite coming to terms with the fact that living rurally would end at some point. RV04 shared the example of his brother who has been living with a slowly

progressing cancer for a couple of years. RV06 discussed how his teenage son had battled cancer for many years and lived several years beyond the expectations of his physician. Two veterans, RV03 and RV05, described how family members provided basic palliative care, although neither of them was able to define palliative care. RV05 did not know what palliative care was, and he was not comfortable guessing about it. This same participant did provide an example of basic palliative care while describing the serious health conditions of his parents:

My mother had dementia. She, ah, for several years- was just classic dementia. We weren't really sure who she knew at times, and it just wore away at her health, and she finally passed away. My father had a sort of lung cancer. It, ah, originated from black lung disease from working in the underground coal mines. And, ah, he suffered with that before he passed on. Dad was always energetic- he would walk every day in the hills; a real physical person- sports and everything. And, it took all that away from him. He just gradually got to where about the best he could do was just watch tv, hooked up to his tubes...And, my mother- it was just the gradual loss of interest in her church; the people she knew. She always liked to visit- gossip a lot- talk with folks- that gradually went away. It was just a symptom that was building and building until she wasn't the person she used to be...My sisters lived right next door to them, and so they [sisters] were always right there caring for them [parents]. And, also, a friend of the sisters....They had very little hospital care. They didn't spend much time in the hospitals at all. They were mostly at home with my sisters watching over them- and this friend that would spend nights with them when they [sisters] couldn't be available... It worked really well for them. It did. Her heart just gave out, finally- right at the end, and they took her to the hospital, and she died right there. And, my dad was in the hospital for maybe a week [pause] before he died.

Discussion

This study explored the perceptions of palliative care among six male veterans living in rural areas. Although the rural dwelling veterans were unable to define palliative care and were uncertain about its meaning, all of them were able to describe serious chronic conditions that lasted, in some cases, many years. All the six rural veterans were familiar with hospice care, although they did not associate palliative care with hospice care. Five of the six veterans did not perceive palliative care to be end-of-life care. It is difficult to compare the results of this study with the findings of other published research works. Similar to the findings of McIlfatrick et al. (2014) and Golla et al. (2014), the lack of understanding about palliative care was found among these rural veterans; however, this lack of understanding was unrelated to their confusion that palliative care was end-of-life care (McIlfatrick et al., 2014), or that palliative care was specialized care for people with cancer (Golla et al., 2014). The perceptions of palliative care being synonymous with end-of-life, as reported by Dembinsky (2014), were related to the participants' negative perceptions about palliative care experiences in that they were often delivered near the end-of-life. Golla and colleagues (2014) found the perceptions of palliative care among adult participants with multiple sclerosis mirrored physicians' perceptions that palliative care was not applicable to multiple sclerosis. Although the rural veterans participating in this study lived in a rural area, they did not share a common condition or experience similar to the rural Aboriginal participants (Dembinsky, 2014) or adults with multiple sclerosis (Golla et al., 2014). Notably, Golla et al. (2014) did not define palliative care for the participants; similarly, palliative care was not defined for the rural veterans participating in this study. If the participants' perceptions about palliative care had been influenced by the perceptions held by

their healthcare providers (Golla et al., 2014) or by their experiences with hospice or end-of-life (McIlfatrick et al., 2014), why do rural veterans (1) have no idea what palliative care is, and (2) why do the rural veterans not perceive palliative care to be, in part, hospice care or end-of-life care?

Conclusions

Concurrent palliative care, when offered as a critical component of primary care across rural areas, has the potential to improve the quality of life and healthcare for rural dwelling veterans with serious chronic conditions who define health as being able to do what they want to do. Managing the bothersome symptoms associated with serious chronic conditions may keep rural veterans active for a longer period and allow them to age in place. However, further palliative care education is needed for rural veterans, nurses and other healthcare professionals who provide their care. Implications for practice include: educating providers and nurses about the broader scope of palliative care along with the benefits of concurrent palliative care, promoting palliative care education among rural veterans and rural communities, and facilitating access to concurrent palliative care throughout rural areas.

Suggested future research should focus on preparation of professional caregivers and family members in the concept of palliative care for improving quality of life, discovering opportunity and access barriers to this type of care in more remote areas. Additionally, future studies should be completed on veteran engagement in palliative care education in a rural community-based or small group settings. This future research should focus on outcomes related to basic palliative care knowledge, the location and timing of this type of care delivery, the differences between hospice and palliative care, and identification of serious chronic conditions and bothersome symptoms for which concurrent palliative care could be of benefit.

References

- Aslakson, R., Koegler, E., Moldovan, R., Shannon, K., Peters, J., Redstone, L., ... Pronovost, P. (2013). Intensive care unit nurses and palliative care: Perceptions and recommendations. *Journal of Pain & Symptom Management*, 45(2), 419–420. <https://doi.org/10.1016/j.jpainsymman.2012.10.123>
- ATLAS.ti Scientific Software Development GmbH (2016). ATLAS.ti (Version 7.5.15) [Computer software]. Berlin, Germany: ATLAS.ti Scientific Software Development GmbH
- Bolin, J. N., Bellamy, G. R., Ferdinand, A. O., Vuong, A. M., Kash, B. A., Schulze, A., & Helduser, J. W. (2015). Rural Healthy People 2020: New decade, same challenges. *The Journal of Rural Health*, 31(3), 326–333. <https://doi.org/10.1111/jrh.12116>
- Braun, V., & Clarke, V. (2008). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: SAGE Publications.
- Cromartie, J. (2016). USDA ERS - Population & Migration. Retrieved May 19, 2017, from

<https://www.ers.usda.gov/topics/rural-economy-population/population-migration/>

- Dembinsky, M. (2014). Exploring Yamatji perceptions and use of palliative care: An ethnographic study. *International Journal of Palliative Nursing*, 20(8), 387–393. <https://doi.org/10.12968/ijpn.2014.20.8.387>
- Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2014). Multiple sclerosis and palliative care – perceptions of severely affected multiple sclerosis patients and their health professionals: a qualitative study. *BMC Palliative Care*, 13(1), 1–23. <https://doi.org/10.1186/1472-684X-13-11>
- Hargadon, A., Tran, Q., Stephen, K., & Homler, H. (2017). A Trial of concurrent care: Shedding light on the gray zone. *Journal of Palliative Medicine*, 20(2), 207–210. <https://doi.org/10.1089/jpm.2016.0279>
- Holder, K. A. (2017). *Veterans in Rural America: 2011 - 2015* (American Community Survey Reports No. ACS-36) (p. 22). Washington, DC: U.S. Census Bureau. Retrieved from <https://www.census.gov/content/dam/Census/library/publications/2017/acs/acs-36.pdf>
- Kavalieratos, D., Mitchell, E. M., Carey, T. S., Dev, S., Biddle, A. K., Reeve, B. B., ... Weinberger, M. (2014). “Not the ‘Grim Reaper Service’”: An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *Journal of the American Heart Association*, 3(1), e000544. <https://doi.org/10.1161/JAHA.113.000544>
- Kozlov, E., McDarby, M., Reid, M. C., & Carpenter, B. (2017). Knowledge of palliative care among community-dwelling adults. *American Journal of Hospice and Palliative Medicine*, 35(4), 647–651. <https://doi.org/10.1177/1049909117725725>
- LeBlanc, T. W., O'Donnell, J. D., Crowley-Matoka, M., Rabow, M. W., Smith, C. B., White, D. B., ... Schenker, Y. (2015). Perceptions of palliative care among hematologic malignancy specialists: A mixed-methods study. *Journal of Oncology Practice*, 11(2), e230–e238. <https://doi.org/10.1200/JOP.2014.001859>
- Lee, H. J., & McDonagh, M. K. (2013). Updating the rural nursing theory base. In *Rural nursing concepts, theory, and practice* (4th ed., pp. 15–33). New York, NY: Springer Publishing Company.
- Long, K. A., & Weinert, C. (2013). Rural nursing: Developing the theory. In *Rural nursing concepts, theory, and practice* (4th ed., pp. 1–14). New York, NY: Springer Publishing Company.
- Maxwell, J. A. (2013). *Qualitative research design an interactive approach* (3rd ed.). Thousand Oaks, CA: SAGE Publications.
- McIlfatrick, S., Noble, H., McCorry, N. K., Roulston, A., Hasson, F., McLaughlin, D., ... Craig,

- A. (2014). Exploring public awareness and perceptions of palliative care: A qualitative study. *Palliative Medicine*, 28(3), 273–280. <https://doi.org/10.1177/0269216313502372>
- Murray, S. A., Kendall, M., Mitchell, G., Moine, S., Ambias-Novellas, J., & Boyd, K. (2017). Palliative care from diagnosis to death. *British Medical Journal*, 356: j878. <https://doi.org/10.1136/bmj.j878>
- Polit, D. F., & Beck, C. T. (2012). *Nursing research generating and assessing evidence for nursing practice* (9th ed.). Philadelphia, PA: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research bridging the conceptual, theoretical, and methodological*. Thousand Oaks, CA: SAGE Publications.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334–340.
- Tasseff, T. L., & Tavernier, S. S. (2018). Challenges and opportunities to palliative care for rural veterans. In *Rural nursing: Concepts, theory, and practice* (5th ed.). New York, NY: Springer Publishing Company.
- United States Census Bureau. (n.d.). County classification lookup table. United States Census Bureau. Retrieved from <https://www.census.gov/geo/reference/urban-rural.html>
- U.S. Centers for Medicare & Medicaid Services. (n.d.). Hospice & respite care. Retrieved March 15, 2018, from <https://www.medicare.gov/coverage/hospice-and-respite-care.html>
- Verschuur, E. M., Groot, M. M., & van der Sande, R. (2014). Nurses' perceptions of proactive palliative care: A Dutch focus group study. *International Journal of Palliative Nursing*, 20(5), 241–245. <https://doi.org/10.12968/ijpn.2014.20.5.241>
- VHA Office of Rural Health. (2016, September). Rural veterans. U.S. Department of Veterans Affairs. Retrieved from https://www.ruralhealth.va.gov/docs/ORH_RuralVeterans_infosheet_FINAL508.pdf
- Weil, J., Weiland, T. J., Lane, H., Jelinek, G. A., Boughey, M., Marck, C. H., & Philip, J. (2015). What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department. *Palliative Medicine*, 29(4), 239–301. <https://doi.org/10.1177/0269216314560801>
- World Health Organization. (2016). Noncommunicable diseases and their risk factors. Retrieved September 19, 2016, from <http://www.who.int/ncds/management/palliative-care/en/>

CHAPTER V: Discussion and Recommendations

Overview

The specific study aims of this mixed methods dissertation research study were to (1) explore and compare the perceptions and palliative care among rural dwelling providers, nurses, adults, and veterans; and (2) explore the relationship between knowledge and perceptions of palliative care held by providers and nurses who practice in rural areas.

Understanding rural perceptions of palliative care is an important first step to transforming healthcare in rural and highly rural areas of the United States. The fifth chapter is divided into four major sections; Integration of Findings, Discussion, Implications, and Conclusions.

Integration of Findings

Review of the Results by Manuscript

First manuscript. The first manuscript presented the results of the integrative literature review related to the perceptions of palliative care among rural providers, nurses, and adults. The integrative review provided the evidence supporting the gaps in the research and provided support for conducting the research. The results were organized thematically, and the following themes were identified based on the frequency of themes across nine articles. The themes were organized by group. The themes identified suggest palliative care is largely thought of as synonymous with end of life care, incongruent with aggressive treatment, and a source of confusion and uncertainty (Manuscript 1).

Key themes related to providers (Manuscript 1) included palliative care is perceived as: (1) Synonymous with end-of-life care; (2) When treatment ends; (3) A source of concern; (4) More philosophical than reimbursable. Key themes related to rural nurses (Manuscript 1) included: (1) Uncertain; (2) When treatment ends; (3) Synonymous with end-of-life care; and (3)

A form of patient advocacy. The key themes related to rural adults (Manuscript 1) included: (1) Death, dying and end-of-life; (2) Confusing; (3) Reinforced by experiences.

Second manuscript. The two specific study aims were addressed in the second manuscript; (1) to explore and compare the perceptions of palliative care among rural providers, nurses and adults; and (2) explore the relationship between knowledge and perceptions of palliative care held by providers and nurses who practice in rural areas (Manuscript 2). For this manuscript, the findings from the rural veteran group ($n = 6$) were aggregated and reported as part of the rural adult group. Themes were reported according to frequency within the interviews across the three rural groups. The key themes identified (Manuscript 2) included: (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. Theoretical saturation was reached in two rural groups, nurses and adults. However, theoretical saturation was not reached in the difficult-to-recruit rural provider group.

In addition to key themes, the Palliative Care Knowledge Test (PCKT) was used to measure the palliative care knowledge of rural providers and nurses (Manuscript 2). The PCKT instrument was first validated in Japanese prior to translating the PCKT into English (Nakazawa et al., 2009) and use of the PCKT in the United States had only been reported with a small group of rural nurses (Evans, 2016). Use of the PCKT has not been reported with providers. However, Nakazawa and colleagues' (2009) development and testing of the instrument followed established methods and standards. Reliability measures, such as stability (interclass correlation coefficient), internal consistency (Kuder-Richarson), equivalence (Kappa) and validity (item analysis and item response theory) are considered the standards of measurement and reporting

for instruments (Souza et al., 2017). A panel of nine palliative care experts, including palliative care physicians, were involved in the development and testing of the PCKT; and internal consistency was reported to be 0.81 (Nakazawa et al., 2009). In this dissertation research study (Manuscript 2), internal consistency was calculated ($\alpha = 0.77$) based on the sample of 51 participants and found to be acceptable (Manuscript 2). Internal consistencies between 0.70 to 0.95 are considered acceptable (Tavakol & Dennick, 2011). Mean PCKT total scores were 12.29 (61.45%) for the rural provider group and 10.48 (52.4%) for the rural nurse group; the difference in mean PCKT total scores and domain scores were nonsignificant (Manuscript 2) with the exception the rural provider group scores for the Dyspnea Domain ($M 3.29$, $SD .76$) were statistically significantly higher than the score for the rural nurses ($M 2.32$, $SD 1.20$, $p < .05$). Differences between rural providers and nurses related to other scores, such as the PCKT total score or the remaining four domain scores, were nonsignificant (Manuscript 2). Difference in PCKT total scores or domains scores between rural providers and nurses who reported completing some form of palliative care education and those who did not report some form of palliative care training were nonsignificant (Manuscript 2). An exploratory categorical principal component analysis (CATPCA) conducted to explore the variance in PCKT knowledge scores explained 34 percent ($d = 0.90$) of the variance between scores in the model (Manuscript 2). The constructs, Maturity and Rural Investment, were supported by the sample characteristics of the rural providers and nurses who participated in the study.

Third manuscript. Evidence related to rural veterans was presented in the third manuscript and addressed a portion of the primary specific study aim through the exploration of the perceptions of palliative care among rural veterans. Key themes related to the rural veterans

group included: (1) Uncertainties about palliative care; (2) Where and when; (3) Palliative care is not hospice care; and (4) Opportunities.

Comparison of Themes

A comparison of themes addresses the primary specific study aim to explore and compare the perceptions of palliative care among four rural dwelling groups. Appendix F provides a side-by-side comparison of the three manuscripts and corresponding themes. The predominant themes related to perceptions of palliative care as end of life care were associated with providers, nurses, and adults in the first and second manuscripts and include the following themes:

Synonymous with end-of-life and *Death, dying and end-of-life* (Manuscript 1) and *Palliative care is comfort for the dying or end-of-life care* (Manuscript 2).

Rural providers. Four of the five providers defined palliative care broadly; however, contrasting statements presented during the interviews suggest that palliative care is practiced narrowly and reserved for the end-of-life (Manuscript 2). It is unknown whether these contrasting statements are a result of reimbursement concerns as mentioned by Golla and colleagues (2014) and LeBlanc and colleagues (2015) and reported in the first manuscript; or a result of narrowly defined, hospice-associated, academic preparation and educational experiences as reported in the literature (Fitzpatrick, Heah, Patten, & Ward, 2017).

Rural nurses. Similar to the rural providers, the nurses in this study mainly perceived palliative care to be end-of- life care. In contrast to providers, nurses were admittedly confused about the differences between palliative care and hospice care; and defined the timing of palliative care in restrictive terms supporting a definition of palliative care consistent with end-of-life care, and this finding is consistent with the literature (Manuscript 2).

Comparing the themes related to nurses, one theme identified in the literature, *palliative care is a form of patient advocacy* (Manuscript 1), did not emerge with the rural nurses who participated in semi-structured interviews in this dissertation research study (Manuscript 2). Golla et. al (2014), in a study of nurses who provided care to patients with multiple sclerosis in Germany, discussed how the nurses perceived palliative care could add an extra layer of support for patients with multiple sclerosis. Weil and colleagues (2015), who conducted a study involving emergency department nurses in Australia, reported advocacy as fast-tracking patients with advanced cancer through triage to decrease the patients' wait and suffering. Verschuur and colleagues (2014), in a study of palliative care nurses conducted in the Netherlands, described advocacy among palliative care nurses for patients whom the nurses provided care. Similarities in data collection methods amongst the three studies published in the literature (Golla et al., 2014; Verschuur et al., 2014; Weil et al., 2015) may explain similarities related to the patient advocacy theme as all three studies collected data using focus group interviews. This dissertation research study used one-to-one semi-structured interviews.

Rural adults. The results of the rural dwelling adults and rural veterans were reported in aggregate as rural adults (Manuscript 2). Of the 13 participants, four participants (31%) had never heard of the term palliative care. An internet-based study of 301 participants recruited through Amazon's online marketplace conducted by Koslov, McDarby, and Reid (2017) used the Palliative Care Knowledge Scale (PaCKS) with a sample of 301 participants recruited through Amazon's online marketplace and found less than half (46%) of the participants had heard of palliative care. Higher PaCKs scores were reported for older adults and women between the ages of 46 and 64 (Kozlov, McDarby, Reid, & Carpenter, 2017). Kozlov and colleagues (2017)) reported the most incorrectly answered question pertained to palliative care as appropriate only

for people in the last six months of life, which support the findings of this dissertation research study that the majority of rural providers, nurses, and adults who participated in this dissertation research study perceived palliative care to be comfort for people at the end-of-life (Manuscript 2). The percentage of rural adult participants in this dissertation research study who had never heard the term palliative care was lower than the percentage reported by Kozlov and colleagues (2017); 31 percent compared with 46 percent. Several differences related to differences in the samples may have contributed to differences in results. Compared with the adults who participated in the study by Kozlov et al. (2017), a greater percentage of participants in this dissertation research study were male (54% compared with 48%); older (77% age 55 or older compared with 32%); married (85% compared with 33%); and less educated (69% reported some college or a higher degree compared with 85%). Additionally, data collection techniques were different between the studies. Information about whether the participants lived in rural or urban settings were not reported in the study by Kozlov, McDarby, and Reid (2017).

Rural veterans. More rural veterans, when compared to rural adults, were uncertain about the meaning of palliative care. Two veterans had never heard of the term palliative care; three veterans were familiar with the term palliative care but were uncertain of the meaning; and one veteran inaccurately defined palliative care as occurring after hospice (Manuscript 3). Interestingly, all rural veterans and all rural adults in this study provided a fairly accurate definition of hospice care (Manuscripts 2 & 3). One veteran, RV04, who speculated that palliative care occurred at the end-of-life, perceived palliative care to be different than hospice care; occurring after hospice care. (Manuscript 3). The theme *Palliative care is not hospice care*, is a finding unique to the rural veterans interviewed and is not represented in the literature.

The perceptions of veterans in this study differ from the rural adults in this study and in

the literature, who mostly perceived palliative care to be end-of-life care, hospice care, or death and dying (Dembinsky, 2014; Golla, Galushko, Pfaff, & Voltz, 2014; McIlfatrick et al., 2014).

The literature supports that positive or negative experiences related to palliative care reinforce perceptions. Negative experiences of palliative care as end-of-life care reinforced perceptions that palliative care was end-of-life for patients and families who received late referrals to palliative care, such as reported by Dembinsky (2014). Similarly, researchers of a study conducted in Canada found patients with advanced cancer and their families, who had negative perceptions prior to experiencing palliative care, reported positive perceptions after receiving palliative care (Zimmerman et al., 2016). All rural veterans in this dissertation research study, were able to provide examples of family members or friends with serious illnesses, and most rural veterans shared experiences, many positive, with hospice care. Yet, none of the rural veterans associated palliative care with hospice care, and five of the six did not perceive palliative care to be end-of-life care.

Possible explanations for this finding were explored (Manuscript 3). Four of the rural veterans lived in highly rural areas, one rural veteran lived within three miles of a small town, and one rural veteran lived in a small town. Veterans ranged in age from 53 to 77 years of age (M 66.8, SD 8.0). Three of the veterans receive at least a portion of their care from VA clinics and medical centers. Two of the veterans reported service connected disabilities, all veterans were Caucasian males with education ranging from high school graduates through college graduates with bachelors' degrees. Five of the veterans were Vietnam era and one veteran served in Desert Storm. The reason for the unique finding, present among all six veterans, is not explained by the sample characteristics.

Additionally, four of the veterans likely receive care from community healthcare providers based on their length of service and lack of service-connected disabilities. McIlfatrick and colleagues (2014) and Golla and colleagues (2014) referenced providers and nurses as one of the sources at least partially responsible for perceptions of palliative care among adults. If this is true, are VA providers with access to VA concurrent palliative care services, and rural providers and nurses who perceive palliative care to be synonymous with end-of-life care, not talking about services with their patients? If this were true, then how would the differences between rural adults and rural veterans be explained? Is there something in the shared experiences of veterans related to military service that may explain this unique finding? Designing a larger follow-on study exploring the perceptions of palliative care among rural veterans may help to determine if this finding is unique only to this small group of rural veterans or present in the larger rural veteran population. Time did not permit further exploration of this issue within the context of this dissertation research study.

Integration of the Results

The integration of the results addresses the two specific study aims of this dissertation research. Results of the integrated findings from the three manuscripts are presented in Appendix F, Three Manuscripts – Integration of Themes. The themes of each manuscript are presented (Manuscript 1, 2, and 3) in columns. Beneath the columns, the relationship or linkage of the themes, within and between each of the three manuscripts, is presented.

An integration of the themes, PCKT scores, and exemplar quotes is found in Appendix G, Three Manuscripts – Integration of Results. The bolded themes were identified in the existing literature (Manuscript 1). Exemplar quotes provided below the bolded themes (Manuscript 1) were identified in this dissertation research (Manuscript 2) and the qualitative account of rural

veterans (Manuscript 3). The integration of the results reported in all three manuscripts shows how the findings of this dissertation research study are confirmed (where appropriate) by the existing literature and how the evidence of this dissertation research study adds to the body of knowledge related to the perceptions of palliative care.

Summary of the Integration of the Three Manuscripts

The integration of the findings of the three manuscripts collectively address the two specific study aims of this dissertation research study. The relatively low palliative care knowledge scores among rural providers and nurses, as measured by the PCKT (Manuscript 2) and supported in the current literature (Manuscript 1) and confirmed by the exemplar quotes (Manuscripts 2 and 3). One unique finding related to perceptions of palliative care among rural veterans, *Palliative care is not hospice care* (Manuscript 3), was not identified in the existing literature (Manuscript 1) or in the remaining three rural dwelling groups represented in this dissertation research study (Manuscript 2).

Manuscript Decisions

Additional themes not reported in the manuscripts. The decision concerning what themes to include in the manuscripts were based upon whether or not the themes addressed the two specific study aims. Each participant was asked to define health. Most participants were asked if they, or someone they knew, had a serious illness. Although themes were developed based on responses to these questions, the themes were not included in the themes reported in the manuscript related to the full mixed methods study (Manuscript 2). These themes, although important to rural health and rural nursing theory, did not directly address the specific aims of this dissertation research study. Explaining these themes and how the themes were related to palliative care introduced new concepts based on additional theories.

Although not appropriate to include in the manuscripts related to the two specific study aims, these additional themes may support future studies, which will provide additional evidence helpful to palliative care education and integration efforts to improve access in rural areas, such as: (1) how do individual definitions of health contribute to chronic disease management in rural areas; (2) what is the relationship between personal definitions of health and palliative care among rural dwelling adults; (3) to what extent do personal definitions of health predict acceptance or rejection of palliative care education; and (4) For rural adults who perceive health and chronic illness can coexist, what are their criteria for defining health; (5) Exploring the potential for concurrent palliative care among rural adults living with chronic disease, (6) Exploring personal definitions of health and quality of life among rural veterans with serious chronic conditions.

Other items not included. Some items used for data collection and analysis were not included in the manuscripts. The journals selected for publication allow a maximum of three to five tables, figures, or illustrations. Certain items important to the dissertation research processes and described in the manuscripts (Manuscripts 1 and 2), but not necessarily included, are provided in the Appendices (Appendix A: Semi-Structured Interview Guide; Appendix B: Demographic Surveys; Appendix C: Variables and Level of Measurement; Appendix D: Palliative Care Knowledge Test (PCKT); Appendix E: Permission to Use the PCKT).

Discussion

Limitations

Several limitations about this mixed methods dissertation research study are worth noting. The scope of this research was limited by time and funding. Efforts were made to plan efficient travel routes throughout the expansive, geographically determined study area. People

who live in rural and highly rural areas are spread out across large geographic areas. The expansive setting allowed the opportunity to include potential participants representing approximately 29,000 people spread out across more than 8,500 square miles. Four of the rural veterans and three of the rural dwelling adults who participated in this study live in some of the most remote areas and may not have had the opportunity to participate had the setting been defined differently. Data collection methods may have limited participation. Using additional data collection methods, such as email, Internet, and telephone may conserve resources in future studies involving rural providers and nurses. However, internet and cell phone coverage are limited in much of the geographically defined area of this study. One participant, who did not have a telephone, approached the researcher and inquired about participating after reading the recruitment poster stapled to a rural message board.

Recruitment strategies may be a limitation. Social media was not used as a recruitment strategy, which may have limited participation from younger rural adult and veteran participants. Adding social media recruitment methods may have resulted in recruiting additional, younger rural participants for this study based on the median age in geographic area of the study, which ranged from 42.1 to 52.8 years of age (Deloitte, Datawheel, & MIT Media Lab, n.d.). Rural adult and veteran participants in this exploratory dissertation research study ranged in age from 53 to 77 years of age and their perceptions of palliative care may be different from those obtained from a sample of younger participants.

The interviews were relatively short in length, which may have limited the richness of responses although meeting purpose of the research to explore and compare perceptions. Following completion of the first three interviews, interviewing techniques were discussed with a more experienced researcher who provided suggestions for improvement, including different

phrasing and words to use when participants were not familiar with the term palliative care. Suggestions were implemented with subsequent interviews. The convergent parallel design, and similar findings in the literature supported the themes identified using thematic analysis within this study. A second researcher independently coded the first three interviews and 30 percent of the remaining interviews validating the qualitative analysis.

Another limitation may be theoretical saturation was not obtained in the difficult-to-recruit rural provider group. Consensus on what constitutes the correct number of interviews does not exist; however, the sample size should be large enough to accomplish the purpose of the research given the available time and resources (Ravitch & Carl, 2016). Time and resources did not allow recruitment to continue. Different recruitment strategies, more time, and different data collection methods may increase participation from rural providers.

Generalizability may be another limitation. The quantitative sample was relatively small, and the provider and nurse groups were unequal sizes. The sample sizes obtained were adequate to address the exploratory purpose of this mixed methods dissertation research study to explore and compare the perceptions of palliative care among the four rural groups. Small sample sizes in mixed methods designs are not as problematic as in single method designs (Creswell, 2014). However, the goal of exploratory designs is not generalizability (Vogt, Gardner, & Haeffele, 2012).

Lack of statistical power is a possible limitation. The post hoc power analysis showed the quantitative component of the study was significantly underpowered for a two-group design. Low power increases the chance of a Type I error, incorrectly rejecting the null hypothesis; thus, a result appears to be statistically significant when it is not (Meyers, Gamst, & Guarino, 2013). An exploratory post hoc power analysis calculated using the total sample ($n = 51$) found the

power to be 0.96 ($d = 0.50$). The lack of power in a two-group design was minimized using a mixed methods design (Creswell, 2014). The multiple method design, convergent analysis with merging and comparing results, and the use of exemplar quotes to support the thematic analysis reduced threats related to lack of power in an exploratory study. Many of the results in this study were confirmed through comparison with previous studies. Variations in findings between this study and the current evidence were explored to identify possible explanations for differences in findings. Additionally, ninety-nine survey packets were provided to 19 organizations and 51 surveys were analyzed (51.5% response rate), which is a reasonably representative sample of the rural population of providers and nurses within the geographically defined study area (Manuscript 2) lending support to the results obtained in this exploratory study.

Limited Research

A limited amount of research was identified related to perceptions of palliative care among rural providers, nurses, and adults (Manuscript 1). Most of the research was qualitative, and only three of the nine articles reported in the integrative literature review were conducted in the United States. Five of the articles explicitly identified rural participants were included in the sample; sample characteristics for rural participants were not reported in three of these articles. The remaining four articles implied the sample included rural participants based on the setting. Of the nine studies, only two studies focused on a homogeneous rural sample and described the rural setting, and only one of these studies was completed using a small rural sample in the United States. Perceptions of palliative care among rural dwelling veterans were absent in the literature and no articles were identified in the databases searched. The results of the integrative literature review indicated a significant gap in the research related to perceptions of palliative care among rural dwelling providers, nurses, adults, and veterans (Manuscript 1).

Implications

Implications for Practice

Education. The results of this dissertation research study suggest a need for palliative care education among rural dwelling providers, nurses, adults, and veterans. Changes to medical and nursing academic preparation and continuing medical and nursing education are needed. Medical and nursing academic preparation should strive to include the broad scope of palliative care and provide clinical experiences that reinforce the appropriateness of palliative care at any time in the disease trajectory, from initial diagnosis through the end-of-life. Authors of a qualitative study of continuing education access for rural critical care nurses reported time, travel, and finances were barriers to attending off-site education and recommended alternate educational delivery methods, such as continuing education delivered by webinars and virtual classrooms (Hendrickx & Winters, 2017). Similarly, authors reported cancer education delivered by videoconferencing to providers at 28 sites in Washington and Alaska received positive evaluations; saved time, travel, and costs; and allowed real-time interaction and discussion with other participants similar to in-person education opportunities (Doorenbos et al., 2011). Organizations may consider conducting formal palliative care educational needs analyses for providers and nurses to identify areas of strength and opportunities related to palliative care knowledge.

The End of Life Nursing Education Consortium, (ELNEC) offers palliative care training for nurses in the United States and 96 other countries, and ELNEC courses are offered online, onsite, and in-person (American Association of Colleges of Nursing, 2018). Improvement in nurses' knowledge related to palliative care have been reported post-completion of ELNEC courses (Behr, 2014; Robinson & Fitzgerald, 2012).

The Education on Palliative and End-of-Life Care (EPEC) modules are offered in the United States and 25 countries online and in-person (Northwestern University, 2017). The core training is appropriate for all disciplines; however, specific clinical competencies are available for providers and include modules for emergency medicine and veterans. (Northwestern University, 2017).

Education for rural adults and rural veterans. Kozlov, McDarby, Reid, and Carpenter (2017) suggest palliative care education for adults should be unassuming, use familiar language, provide a high-level overview, and clarify areas of misperceptions and misinformation such as, the difference between palliative care and hospice, and that palliative care can be delivered at the same time as usual treatment at any point in the course of a serious illness. In a review of an abstract by Kozlov and Carpenter (2017), the authors identified nine broad concepts from a review of web-based palliative care information (the nine items were not provided in the abstract) that should be included when developing palliative care education for non-healthcare professionals. Information on this article is provided in the Chapter 5 references and may be of help to rural dwelling providers or nurses creating palliative care education for adults. Rural adults who participated in the dissertation research study spoke highly of their rural providers, nurses, and healthcare facilities. Therefore, rural providers and nurses armed with current, factual palliative care information are the most appropriate community educators. Offering palliative care education using different educational delivery methods allows rural adults and veterans options. Telephone, internet, webinars, videoconferencing, and booklets or paper-based palliative care education allows rural adults to select the best education delivery method for the individual. In the geographic area of this dissertation research, cellular telephone and internet service is limited or not available. The quality of landline telephone services varies.

Community education offerings at senior centers, school auditoriums, libraries, and churches provide ready venues to offer palliative care education in the community, and many locations can accommodate education delivered by videoconferencing or webinars.

Using veterans to educate other veterans about palliative care may be a successful strategy. Veterans understand the challenges of other veterans (Ahern et al., 2015). Trusted rural providers and nurses can help develop and train interested rural veterans to deliver palliative care education to small groups of fellow veterans in the rural and highly rural areas where they live. Currently, a lack of community appropriate, standardized palliative care education exists. The U.S Department of Veterans Affairs (VA) provides tools and information about palliative care. Several of the tools, such as a self-assessment for caregivers and a decision-making guide, can be printed directly from the website; this is especially helpful for point-of-care education when talking with rural veterans and families who may need palliative care education and do not have internet access (U.S. Department of Veterans Affairs, 2017). The palliative care education and tools offered on the VA website may be useful as an educational bridge and are considered introductory rather than comprehensive.

Implications for Future Research

Rural providers. Future studies related to rural providers might explore the associations between reimbursement and practice in rural areas. Talking with administrators of several small hospitals in the geographically designed study area, narrow operating margins are common. Many questions exist about palliative care and reimbursement. Additionally, exploration of the foundation for contradictory statements between knowing the broad applicability of palliative care and describing the practice of providing end-of-life care. Without a clear understanding of the foundation of the perceptions and practices related to palliative care, it is unlikely attempts at

transforming rural healthcare delivery models to include concurrent palliative care as a critical component of primary care in rural areas will be successful.

Rural nurses. Future studies related to rural nurses and palliative care might include methodological triangulation; using semi-structured interviews, focus groups, and surveys with open-ended responses to collect qualitative data. Methodological triangulation uses different data collection methods to increase the validity of the research (Ravitch & Carl, 2016). This mixed methods dissertation research study was conducted using a convergent parallel design with separate methods, separate analysis, and a mixing and comparison of the quantitative and qualitative results in the final converged analysis thereby retaining the strengths of both methods while minimizing the threats of each method (Creswell, 2014). Using different data collection methods within the qualitative component may yield different results in a larger scale study of rural nurse perceptions of palliative care.

Rural adults. Future studies of rural adults and palliative care might include the use of a pretest-posttest design, with or without randomization, and a palliative care education intervention. Use of the previously validated, 13-item, Palliative Care Knowledge Scale (PaCKS) could be used to measure palliative care before and after an education intervention. Although the PaCKS was delivered using the internet, many areas within the geographically designed area of the study lack internet service, cellular telephone service, and dependable landline telephone service. Schools and libraries throughout the area have the technology and meeting spaces to conduct education and allow access to online or electronic surveys. Having multiple methods of administering the PaCKS may be helpful when planning a large-scale study of rural adults and palliative care. Use of an internet-based survey tool may gain interest from younger participants who were not a part of this dissertation research study.

Rural veterans. Unique differences were found related to the rural veterans in this study; specifically, the rural veterans in this study did not know what palliative care was but did not associate palliative care with hospice care. Future studies exploring whether this finding is similar among other rural veterans may help with designing education targeted to rural veterans. The source of rural veterans' healthcare services and where rural veterans seek health-related information may add value to answering this question. Additional research is needed to determine whether rural veterans respond better to palliative care education delivered by health care providers or other veterans trained to deliver palliative care education.

Other areas of research. Certified medical assistants (CNAs), certified nursing assistants, and emergency medical technicians were not included in this dissertation research study. These dedicated unlicensed staff are important to sustaining healthcare delivery in rural areas. Two surveys completed by CNAs were returned and excluded from the analysis. However, future studies related to palliative care in rural areas might include unlicensed staff and their role in palliative care delivery in rural areas. Other research opportunities related to the rural dwelling population include exploring the roles of retirees, family members, and other rural volunteers in educating and delivering basic palliative care and palliative care education in rural and highly rural areas.

Conclusions

Three manuscripts were used to present the mixed methods research study exploring and comparing the perceptions of palliative care among rural dwelling providers, nurses, adults, and veterans. A convergent parallel design was used to address two specific study aims. The specific study aims were:

1. To explore and compare the palliative care perceptions among rural dwelling providers, nurses, and veterans.
2. To explore the relationship between knowledge and perceptions of palliative care held by providers and nurses who practice in rural areas.

First specific study aim (Study Aim 1.). The research successfully addressed the first specific study aim to explore and compare the perceptions of palliative care among the four rural dwelling groups. Rural dwelling providers, nurses, and adults, largely perceived palliative care to be synonymous with end-of-life care. The majority of providers correctly defined palliative care yet described end-of-life care leading to further questions about palliative care practices in rural areas. Rural nurses were uncertain about the differences between palliative care and hospice. Rural adults and veterans were confused about the term palliative care. Similar to findings in other studies, nearly half of the rural adults perceived palliative care to be hospice or end-of-life care. All rural adults and veterans had heard the term hospice and provided fairly accurate definitions of hospice care. Yet, a unique finding emerged in the rural veteran group; none of the veterans perceived palliative care to be hospice care. This finding was dissimilar from the perceptions of rural adults who participated in this study and has not been reported previously in the literature. Explanations for this unique finding among the rural veterans were explored, but possible explanations for the unique finding were not identified and further research is recommended.

Second specific study aim (Study Aim 2.). The research successfully addressed the second specific study aim to explore the relationship between knowledge and perceptions of palliative care held by providers and nurses who practice in rural areas. For the 51 rural providers and nurses who participated in the quantitative component of the study, PCKT scores

were low (61.45% for providers, 52.4% for nurses) suggesting poor knowledge related to palliative care. Poor palliative care knowledge was supported in the convergent analysis comparing the quantitative PCKT knowledge scores with the qualitative interview results of the 12 providers and nurses. Consistent with previous studies of provider and nurse perceptions of palliative care, rural providers and nurses in this study largely perceived palliative care to be providing comfort at the end-of-life after curative or aggressive treatment has stopped. Most of the rural providers interviewed provided a broad definition of palliative care. In contrast, all but one nurse defined palliative care as end-of-life care. The one nurse who did not define palliative care as end-of-life care was uncertain about the definition. Two constructs, Maturity and Rural Investment, explained 36 percent of the variance in the PCKT knowledge scores. The sample characteristics of participants in both components of the study support that providers and nurses who practice in the geographic area studied are experienced and have lived and practiced in rural areas for considerable time, which supports to the construct of Maturity and Rural Investment.

The significance of this research. For the 47 million people who live in rural areas of the United States (Cromartie, 2016), and the small numbers of providers and nurses who dedicate their practices to providing health care for rural populations, the results of this research exploring and comparing perceptions of palliative care among rural providers, nurses, adults and veterans is a small, but important, step towards transforming healthcare in rural America and increasing access to palliative care in rural areas.

Rural-urban health care disparities continue to grow. Rural dwelling adults, on average, are older, live on smaller incomes, are less healthy, and have less access to healthcare compared to urban dwelling adults (Bolin et al., 2015). Rural veterans, on average, are older and more disabled than the rural non-veterans (Tasseff & Tavernier, 2018). The incidence of chronic

disease increases with age, and by 2030, one in five Americans will be age 65 or older (Centers for Disease Control and Prevention, 2013); the majority will be living with multiple chronic conditions (Gerteis et al., 2014). People living with chronic conditions often experience a decreased quality of life (Centers for Disease Control and Prevention, 2013). Palliative care focuses on improving the quality of life for patients suffering from serious illnesses (Meier & Bowman, 2017).

Solutions to rural healthcare problems, such as access to healthcare services and palliative care, will be solved by the providers, nurses, adults and veterans who live rurally. However, misperceptions and lack of knowledge about palliative care pose significant barriers to transforming healthcare in rural areas; far greater than the limited resources and expansive geography that define the boundaries of rural America.

This research provides a platform to begin the dialogue to improve access to palliative care in rural areas. Dialogue opens the doors for changes to academic preparation and continuing education for providers and nurses. Once educated on the broad scope of palliative care, providers and nurses will be able to address misperceptions about palliative care with colleagues and within rural communities; eventually transforming rural health care delivery models to include concurrent palliative care as a component of comprehensive primary care in rural areas.

Improving palliative care access provides opportunities for rural dwelling people living with serious chronic conditions to improve their quality of life rather than receive comfort *only at the end-of-life*.

References

- Ahern, J., Worthen, M., Masters, J., Lippman, S. A., Ozer, E. J., & Moos, R. (2015). The challenge of Afghanistan and Iraq veterans' transition from military to civilian life and approaches to reconnection. *PLoS ONE*, 10(7), e128599.
<https://doi.org/10.1371/journal.pone.0128599>
- American Association of Colleges of Nursing. (2018). ELNEC End-of-Life Nursing Education Consortium. Retrieved March 6, 2018, from <http://www.aacnnursing.org/ELNEC>
- Behr, D. J. (2014, August 13). Evaluation of impact of End-of-Life Nursing Education Consortium (Elneec) education on registered nurses. Regis University, Denver, CO.
Retrieved from
<https://epublications.regis.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&=1&article=1173&context=theses>
- Bolin, J. N., Bellamy, G. R., Ferdinand, A. O., Vuong, A. M., Kash, B. A., Schulze, A., & Helduser, J. W. (2015). Rural Healthy People 2020: New decade, same challenges. *The Journal of Rural Health*, 31(3), 326–333. <https://doi.org/10.1111/jrh.12116>
- Centers for Disease Control and Prevention. (2013). The state of aging and health in America 2013 (p. 60). US Department of Health and Human Services. Retrieved from
<http://www.cdc.gov/aging/help/dph-aging/state-aging-health.html>
- Creswell, J. W. (2014). *Research design qualitative, quantitative, and mixed methods approaches* (4th ed.). Los Angeles, CA: SAGE.
- Cromartie, J. (2016). USDA ERS - Population & Migration. Retrieved May 19, 2017, from
<https://www.ers.usda.gov/topics/rural-economy-population/population-migration/>

Deloitte, Datawheel, & MIT Media Lab. (n.d.). DATAUSA. Retrieved March 6, 2018, from <https://datausa.io/>

Dembinsky, M. (2014). Exploring Yamatji perceptions and use of palliative care: An ethnographic study. *International Journal of Palliative Nursing*, 20(8), 387–393. <https://doi.org/10.12968/ijpn.2014.20.8.387>

Doorenbos, A. Z., Kundu, A., Eaton, L. H., Demiris, G., Haozous, E. A., Towle, C., & Buchwald, D. (2011). Enhancing access to cancer education for rural healthcare providers via telehealth. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 26(4), 682–686. <https://doi.org/10.1007/s13187-011-0204-4>

Evans, C. A. (2016). Rural long term care nurses' knowledge of palliative care. *Online Journal of Rural Nursing & Health Care*, 16(2), 141–167. <https://doi.org/10.14574/ojrnhc.v16i2.409>

Fitzpatrick, D., Heah, R., Patten, S., & Ward, H. (2017). Palliative care in undergraduate medical education - How far have we come? *American Journal of Hospice and Palliative Medicine*, 34(8), 762–773. <https://doi.org/10.1177/1049909116659737>

Gerteis, J., Izrael, D., Deitz, D., LeRoy, L., Ricciardi, R., Miller, T., & Basu, J. (2014). *Multiple chronic conditions chartbook* (No. AHRQ Q14-0038) (p. 52). Rockerville, MD: Agency for Healthcare Research and Quality. Retrieved from <http://www.cdc.gov/chronicdisease/overview/>

Golla, H., Galushko, M., Pfaff, H., & Voltz, R. (2014). Multiple sclerosis and palliative care - perceptions of severely affected multiple sclerosis patients and their health professionals:

- a qualitative study. *BMC Palliative Care*, 13(1), 1–23. <https://doi.org/10.1186/1472-684X-13-11>
- Hendrickx, L., & Winters, C. (2017). Access to continuing education for critical care nurses in rural or remote settings. *Critical Care Nurse*, 37(2), 66–71. <https://doi.org/10.4037/ccn2017999>
- Kozlov, E., & Carpenter, B. (2017). “What is palliative Care?”: Variability in content of palliative care informational web pages. *American Journal of Hospice and Palliative Medicine*, 34(3), 241–247. <https://doi.org/10.1177/1049909115615566>
- Kozlov, E., McDarby, M., Reid, M. C., & Carpenter, B. (2018). Knowledge of palliative care among community-dwelling adults. *American Journal of Hospice and Palliative Care*, 35(4), 647–651. <https://doi.org/10.1177/1049909117725725>
- LeBlanc, T. W., O’Donnell, J. D., Crowley-Matoka, M., Rabow, M. W., Smith, C. B., White, D. B., ... Schenker, Y. (2015). Perceptions of palliative care among hematologic malignancy specialists: A mixed-methods study. *Journal of Oncology Practice*, 11(2), e230–e238. <https://doi.org/10.1200/JOP.2014.001859>
- McIlfatrick, S., Noble, H., McCorry, N. K., Roulston, A., Hasson, F., McLaughlin, D., ... Craig, A. (2014). Exploring public awareness and perceptions of palliative care: A qualitative study. *Palliative Medicine*, 28(3), 273–280. <https://doi.org/10.1177/0269216313502372>
- Meier, D. E., & Bowman, B. (2017). The Changing Landscape of Palliative Care. *Generations*, 41(1), 74.
- Meyers, L. S., Gamst, G., & Guarino, A. J. (2013). *Applied multivariate research design and interpretation* (2nd ed.). Los Angeles, CA: SAGE Publications.

- Nakazawa, Y., Miyashita, M., Morita, T., Umeda, M., Oyagi, Y., & Ogasawara, T. (2009). The palliative care knowledge test: Reliability and validity of an instrument to measure palliative care knowledge among health professionals. *Palliative Medicine*, 23(8).
<https://doi.org/10.1177/0269216309106871>
- Northwestern University. (2017). Education in palliative and end-of-life care. Retrieved March 6, 2018, from <http://bioethics.northwestern.edu/programs/epec/>
- Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research bridging the conceptual, theoretical, and methodological*. Thousand Oaks, CA: SAGE Publications.
- Souza, A. C. de, Alexandre, N. M. C., Guirardello, E. de B., Souza, A. C. de, Alexandre, N. M. C., & Guirardello, E. de B. (2017). Psychometric properties in instruments evaluation of reliability and validity. *Epidemiologia e Serviços de Saúde*, 26(3), 649–659.
<https://doi.org/10.5123/s1679-49742017000300022>
- Tasseff, T. L., & Tavernier, S. S. (2018). Challenges and opportunities to palliative care for rural veterans. In *Rural nursing: Concepts, theory, and practice* (5th ed.). New York, NY: Springer Publishing Company.
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, 2, 53–55. <https://doi.org/10.5116/ijme.4dfb.8dfd>
- U.S. Department of Veterans Affairs. (2017). Palliative Care - geriatrics and extended care [General Information]. Retrieved March 6, 2018, from https://www.va.gov/GERIATRICS/Guide/LongTermCare/Palliative_Care.asp#
- Verschuur, E. M., Groot, M. M., & van der Sande, R. (2014). Nurses' perceptions of proactive palliative care: A Dutch focus group study. *International Journal of Palliative Nursing*, 20(5), 241–245. <https://doi.org/10.12968/ijpn.2014.20.5.241>

Vogt, P., Gardner, D., & Haeffele, L. (2012). *When to use what research design*. New York, NY: The Guilford Press.

Zimmerman, C., Swami, N., Krzyzanowska, M., Leighl, N., Rydall, A., Rodin, G., ... Hannon, B. (2016). Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*, 188(10), E217–E227. Retrieved from www.cmaj.ca/lookup/doi/10.1503/cmaj.160547

Appendix A

Semi-Structured Interview Guide

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

Bold questions are the structured questions- asked of all participants.

Appendix B

Demographic Surveys

DEMOGRAPHIC SURVEY – Rural Dwelling Adults and Rural Veterans**1. Gender:**

- ☐ Male
☐ Female

2. Marital Status:

- ☐ Single
☐ Married
☐ Divorced
☐ Other: _____

3. What is your ethnicity?

- ☐ Hispanic or Latino
☐ Non-Hispanic
☐ Prefer not to answer

4. What is your race? (*Mark one or more responses*)

- ☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Prefer not to answer

5. Year of birth:

6. Zip code where you LIVE:

7. Zip code where you WORK:

8. How many years have you lived in the area of your current zip code?

_____ years

9. Thinking about your entire life, how many TOTAL years have you lived in a rural area?

_____ years

10. What is the highest degree or level of education you have completed?

- ☐ Less than high school
☐ High school diploma or GED
☐ Some college, no degree
☐ Associates degree
☐ Bachelor's degree
☐ Graduate or Doctoral degree

11. Employment Status:

- ☐ Employed - 35 hours a week or more
☐ Employed - Less than 35 hours a week
☐ Not currently employed

12. If you work, what is your job? _____

13. Are you a veteran?

- ☐ NO
☐ YES

14. Are you a combat veteran?

- ☐ NO
☐ YES

15. Branch of Service:

- ☐ Air Force
☐ Army
☐ Marines
☐ Navy
☐ Coast Guard
☐ Guard/Reserve

16. Length of service:

_____ years

17. Did you retire from the military?

- ☐ NO
☐ YES

18. Service Connected Disability?

- ☐ NO
☐ YES

19. Disability Rating: (please provide %, example: 10%)

20. Era Veteran: (check as many as apply)

- | | | |
|-------------------------------------|---------------------------------------|---|
| <input type="checkbox"/> WWII | <input type="checkbox"/> Vietnam | <input type="checkbox"/> Operation Enduring Freedom |
| <input type="checkbox"/> Korean War | <input type="checkbox"/> Desert Storm | <input type="checkbox"/> Operation Iraqi Freedom |

DEMOGRAPHIC SURVEY – Providers and Nurses**1. Gender:**

- ☐ Male
☐ Female

2. Marital Status:

- ☐ Single
☐ Married
☐ Divorced
☐ Other: _____

3. What is your ethnicity?

- ☐ Hispanic or Latino
☐ Non-Hispanic
☐ Prefer not to answer

4. What is your race? (Mark one or more responses)

- ☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Prefer not to answer

5. Year of birth:

6. Zip code where you LIVE:

7. Zip code where you WORK:

8. How many years have you lived in the area of your current zip code?

_____ years

9. Thinking about your entire life, how many TOTAL years have you lived in a rural area?

_____ years

10. What is the highest degree or level of education you have completed?

- ☐ Some college, no degree
☐ Associates degree or Diploma
☐ Bachelor's degree
☐ Graduate or Doctoral degree

Employment Status:

- ☐ Employed - 35 hours a week or more
☐ Employed - Less than 35 hours a week

11. Position:

- ☐ LPN
☐ RN
☐ PA
☐ CNS
☐ CNM
☐ CRNA
☐ NP
☐ MD or DO

12. Primary practice setting: (Please check the setting where you spend MOST of your working hours)

- ☐ Hospital
☐ Primary Care Clinic
☐ Urgent Care Clinic
☐ VA CBOC
☐ VA Medical Center
☐ Skilled Nursing Facility
☐ Assisted Living Facility
☐ Home Care
☐ Other: _____

13. Primary Area of Specialization: (Example: Oncology, Emergency Medicine, Family Medicine, etc.)

14. Years of Experience/Years of Practice:

15. Palliative Care Training:

- ☐ NO, I have not completed any type of palliative care training
☐ YES, I have completed palliative care training as part of:
☐ Residency
☐ Fellowship
☐ ELNEC
☐ EPEC
☐ CNE or CME seminar course
☐ Other: _____

16. Are you certified in Palliative Care?

- ☐ NO
☐ YES

17. Are you a veteran?☐ NO☐ YES**18. Are you a combat veteran?**☐ NO☐ YES**19. Branch of Service:**☐ Air Force☐ Army☐ Marines☐ Navy☐ Coast Guard☐ Guard/Reserve**20. Length of service:**

_____ years

21. Did you retire from the military?☐ NO☐ YES**22. Service Connected Disability?**☐ NO☐ YES**23. Disability Rating:** (please provide %, example: 10%)

24. Era Veteran: (check as many as apply)☐ WWII☐ Vietnam☐ Operation Enduring Freedom☐ Korean War☐ Desert Storm☐ Operation Iraqi Freedom

Appendix C

Variables and Level of Measurement

Variables and Level of Measurement	
Qualitative Component - Demographics	Palliative Care Perception (Dependent Variable)
Independent Variable	Level of Measurement
Gender	Nominal
Marital Status	Nominal
Ethnicity	Nominal
Race	Nominal
Year of Birth	Ratio
Zip code - WORK	Nominal
Zip code – where you live	Nominal
Years in current zip code	Ratio
Total rural years	Ratio
Level of education	Ordinal
Employment Status	Ordinal
Job	Nominal
Veteran	Nominal
Combat veteran	Nominal
Branch of Service	Nominal
Length of service- in years	Ratio
Retired military	Nominal
Service-connected disability	Nominal
Disability Rating	Ratio
Era Veteran	Nominal
II-Level of education	Ordinal
II-Employment Status	Ordinal
II-Position	Nominal
II-Primary practice setting	Nominal
II-Primary area of specialization	Nominal
II-Years of experience	Nominal
II-Palliative care training	Nominal
II-Palliative care certification	Nominal

II-Years of Experience	Nominal
Variables and Level of Measurement	
Quantitative Component - Demographics	Palliative Care Knowledge (Dependent Variable)
Independent Variable	Level of Measurement
Gender	Nominal
Marital Status	Nominal
Ethnicity	Nominal
Race	Nominal
Year of Birth	Ratio
Zip code - WORK	Nominal
Zip code – where you live	Nominal
Years in current zip code	Ratio
Total rural years	Ratio
Level of education	Ordinal
Employment Status	Ordinal
Job	Nominal
Veteran	Nominal
Combat veteran	Nominal
Branch of Service	Nominal
Length of service- in years	Ratio
Retired military	Nominal
Service-connected disability	Nominal
Disability Rating	Ratio
Era Veteran	Nominal
II-Level of education	Ordinal
II-Employment Status	Ordinal
II-Position	Nominal
II-Primary practice setting	Nominal
II-Primary area of specialization	Nominal
II-Years of experience	Nominal
II-Palliative care training	Nominal
II-Palliative care certification	Nominal
II-Years of Experience	Nominal

Variables and Level of Measurement	
Quantitative Component - PC Knowledge	
PCKT Scores (Dependent Variable)	
Independent Variable	Level of Measurement
Philosophy-Q1: Palliative care should be provided for patients who have no curative treatment	Nominal
Philosophy-Q2: Palliative care should not be provided along with anti-cancer treatments	Nominal
Pain-Q3: One of the goals of pain management is to get a good night's sleep.	Nominal
Pain-Q4: When cancer pain is mild, pentazocine should be used more than an opioid	Nominal
Pain-Q5: When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used	Nominal
Pain-Q6: The effects of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used	Nominal
Pain-Q7: Long-term use of opioids can often induce addiction	Nominal
Pain-Q8: Use of opioids does not influence survival time	Nominal
Dyspnea-Q9: Morphine should be used to relieve dyspnea in cancer patients	Nominal
Dyspnea-Q10: When opioids are taken on a regular basis, respiratory depression	Nominal
Dyspnea-Q11: Oxygen saturation levels are correlated with dyspnea	Nominal
Dyspnea-Q12: Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients	Nominal
Psych-Q13: During the last days of life, drowsiness associated with electrolyte imbalance should decrease comfort	Nominal
Psych-Q14: Benzodiazepines should be effective for controlling delirium	Nominal
Psych-Q15: Some dying patients will require continuous sedation to relieve suffering	Nominal
Psych-Q16: Morphine is often a cause of delirium in terminally ill cancer patients	Nominal
GI-Q17: At terminal stages of cancer, higher calorie intake is needed compared to early stages	Nominal
GI-Q18: There is no route except central venous for patients unable to maintain a peripheral intravenous route	Nominal
GI-Q19: Steroids should improve appetite among patients with advanced cancer	Nominal
GI-Q20: Intravenous infusion will not be effective for alleviating dry mouth in dying patients	Nominal

Appendix D

Palliative Care Knowledge Test (PCKT)

Please answer the questions to the best of your ability.

#	Question	True (T)	False (F)	Unsure (U)
Philosophy				
1	Palliative care should only be provided for patients who have no curative treatments available	T	F	U
2	Palliative care should not be provided along with anti-cancer treatments.	T	F	U
Pain				
3	One of the goals of pain management is to get a good night's sleep.	T	F	U
4	When cancer pain is mild, pentazocine should be used more than an opioid.	T	F	U
5	When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used.	T	F	U
6	The effect of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used.	T	F	U
7	Long-term use of opioids can often induce addiction.	T	F	U
8	Use of opioids does not influence survival time.	T	F	U
Dyspnea				
9	Morphine should be used to relieve dyspnea in cancer patients.	T	F	U
10	When opioids are taken on a regular basis, respiratory depression will be common.	T	F	U
11	Oxygen saturation levels are correlated with dyspnea.	T	F	U
12	Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.	T	F	U
Psychiatric Problems				
13	During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient comfort.	T	F	U
14	Benzodiazepines should be effective for controlling delirium.	T	F	U
15	Some dying patients will require continuous sedation to relieve suffering.	T	F	U
16	Morphine is often a cause of delirium in terminally ill cancer patients.	T	F	U
Gastrointestinal Problems				
17	At terminal stages of cancer, higher calorie intake is needed compared to early stages.	T	F	U
18	There is no route except central venous for patients unable to maintain a peripheral intravenous route.	T	F	U
19	Steroids should improve appetite among patients with advanced cancer.	T	F	U
20	Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	T	F	U

Appendix E

Permission to Use the PCKT

Subject: Re: Request for Permission to use the Palliative Care Knowledge Test

Dear Tamara,

Thank you for your mail. I am Mitsunori Miyashita, Tohoku Univ. Japan.
I was forwarded your mail from Dr. Nakazawa because I manage this scale now.

Although, you can use this scale without permission, if you want, I give you permission.

This scale is translated into English as attached file, however, this English version has not been validated.

In accordance with most recent findings, we think that following two questions are not appropriate now.

Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.

Benzodiazepines should be effective for controlling delirium.

If you have any question, please send me a mail.

Thanks,

Mitsunori

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Appendix F

Three Manuscripts – Integration of Themes

Themes Related to Rural Dwelling Providers, Nurses, Adults, and Veterans		
Manuscript 1 Integrative Literature Review (P1 – P4, N1 – N4, A1 – A3)	Manuscript 2 Mixed Methods Study (MM1 – MM6)	Manuscript 3 Qualitative Account – Rural Veterans (V1 – V4)
<u>PROVIDERS</u> P1. Synonymous with end-of-life care P2. When treatment ends P3. A source of concern P4. More philosophical than reimbursable <u>NURSES</u> N1. Uncertain N2. When treatment ends N3. Synonymous with end-of-life care N4. A form of patient advocacy <u>ADULTS</u> A1. Death, dying and end-of-life A2. Confusing A3. Reinforced by experiences	<u>PROVIDERS, NURSES, ADULTS</u> MM1. Palliative care is comfort for the dying or end-of-life MM2. Palliative Care? Never heard of it. MM3. Uncertainties about the differences between hospice and palliative care MM4. Conflicts between theory and practice MM5. Timing is everything MM6. Experience is a strong teacher	<u>VETERANS</u> V1. Uncertainties about palliative care V2. Where and When V3. Palliative care is not hospice care V4. Opportunities
Related Themes Within and Across the Three Manuscripts (Manuscript 2 Themes are used as the linking theme and are bolded)		
P1 – N3 – A1 – MM1 A2 – N1 – MM2 – V2 P3 – N1 – A2 – MM3 – V4 P4 – MM4 P2 – N1 – N2 – MM5 – MM3 – V3 P1 – P2 – P3 – P4 – N1 – N2 – N3 – N4 – A1 – A2 – A3 – MM1 – MM2 – MM3 – MM4 – MM5 – MM6 – V1- V2 – V4 V3 (theme is unique to the rural veterans)		

Appendix G

Three Manuscripts – Integration of Results

Integrative Literature Review Themes (**Manuscript 1**)
 PCKT measuring palliative care knowledge (Manuscript 2)
 Exemplar quotes (*Manuscripts 2 & 3*)

PROVIDERS (P1 – P4)

PCKT total scores *M* 12.29, *SD* 2.69; correct responses (61.5%)*

P1. Synonymous with hospice or end-of-life care

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

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

P2. When treatment ends

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

P3. A source of concern

“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

P4. More philosophical than reimbursable

“Is it reimbursable? Can you do it? Certainly. Is there benefit to it?... We can maintain people alive much longer than they have a quality of life. We’re able to sustain people much longer, but to what end.” – RP01

NURSES (N1 – N4)

PCKT total scores *M* 9.7, *SD* 2.60; correct responses (48.5%) (Evans, 2016)

PCKT total scores *M* 10.48, *SD* 2.91; correct responses (52.4%)

N1. Uncertain

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

N2. When treatment ends

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

N3. Synonymous with end-of-life

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

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

“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

N4. A form of patient advocacy

(This theme was not supported in this study.)

ADULTS (A1 – A3)**A1. Palliative care is associated with death and dying**

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

“...making them comfortable until they die.” – RD07

*“Palliative care is pretty much just letting someone go- [pause] to die.” – RV04***

A2. Confusing

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

“I’m not exactly sure of the definition... Curative? I would hope so, but I really don’t know.” – RD02

*“...almost like home health care?” – RV01****

A3. Reinforced by experiences

“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.”*

Note: *Use of the PCKT scores with providers was not identified in the literature; **Although the quote provided by RV04 was associated with death and dying, RV04 stated that he thought palliative care and hospice were different, and that hospice occurred before palliative care. ***Palliative care perceptions among rural veterans were not identified in the current literature.