

Exploring perceptions of palliative care among rural dwelling veterans

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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

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Palliative care focuses on improving the quality of life for people and families suffering from serious chronic conditions, such as cancer, multiple sclerosis, rheumatoid arthritis, heart failure, dementia, and diabetes (World Health Organization [WHO], 2016). Palliative care can be delivered at any stage in the disease course, from initial diagnosis through the end-of-life (WHO, 2018). 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% of people globally receive palliative care to address the physical, psychological, emotional and spiritual suffering that often accompanies a serious illness (WHO, 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 component of comprehensive primary care across rural areas. Notably, concurrent palliative care may offer rural dwelling people the opportunity to remain active longer, experience an improved quality of life, and age in place. The number of hospital-based palliative care programs in the United States continues to grow; yet, few outpatient palliative care programs exist outside of urban areas (Meier & Bowman, 2017).

The rural adult population of the United States numbers 47 million and occupies 72% of the land area (Cromartie, 2016). Rural veterans account for 11% of the rural dwelling adult population (Holder, 2017) and roughly 30% of the larger veteran population (U.S. Department of Veterans Affairs [USDVA], Office of Rural Health, 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). On average, veterans who live rurally are older and more disabled than the larger rural population, experience greater healthcare-related disparities than both rural dwelling non-veterans and urban dwelling veterans, and seek healthcare from rural providers and Veterans Administration (VA) providers (Tasseff & Tavernier, 2018).

The Veterans Administration/Veterans Health Administration (VA/VHA) has allocated nearly a third of its budget (32%) health care to rural veterans (USDVA, Office of Rural Health, 2018). Current VA/VHA programs include community-based palliative care (USDVA, Office of

Rural Health, 2018) and concurrent palliative, in the form of hospice care for veterans who are receiving cancer treatments (Mor et al., 2016). The ENABLE III, a randomized controlled trial involving 207 participants at multiple sites in the United States, including veterans receiving cancer treatments at a VA Medical Center, studied the effects of early versus delayed palliative care and concluded that one-year survival rates were statistically significantly higher ($p = .038$) for veterans assigned to the early palliative care or concurrent palliative care intervention group (63%) than the delayed palliative care group (48%) (Bakitas et al., 2015). Earlier ENABLE randomized controlled trials supported that concurrent palliative care, in the form of hospice care, was effective at improving the quality of life for veterans living with cancer (Bakitas et al., 2009) and heart failure (Dionne-Odom 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, or research involving veterans who are currently receiving palliative care (McIlfatrick, et al., 2014; Golla et al., 2014; Dembinsky, 2014;). The complete literature review, conducted as part of the larger mixed methods study was reported in a previous publication (Tasseff, Tavernier, Watkins & Neill, 2018). No literature was identified that addressed rural veterans' perceptions of palliative care prior to enrollment in palliative care services. The lack of published literature about the palliative care perceptions among rural veterans living in the United States indicates a significant gap in the literature. Therefore, the purpose of this research was to explore palliative care perceptions among rural veterans.

Rural veterans are older and have higher rates of disability than the non-veteran rural population. The incidence of chronic conditions increases with age, and people living with chronic conditions experience a decreased quality of life (Centers for Disease Control and Prevention,

2013). Therefore, rural veterans may have the most to gain from concurrent palliative care. Understanding the perceptions of palliative care among rural veterans is the first step to implementing concurrent palliative care in rural areas. 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 concurrent 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.

This article describes the qualitative component of a mixed methods study that explored the perceptions of palliative care among six male rural dwelling veterans. Veterans in the rural area where this study was conducted represent 14% of the population (U.S. Department of Veteran Affairs, 2016) which is higher than the national average.

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 if they are able to continue to do the things they want to do, including work.

Design

This was a qualitative study conducted with a descriptive phenomenological approach. Basic qualitative descriptive designs seek to describe the phenomena of interest while remaining

close to the data (Sandelowski, 2000). Like 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 by discovering commonalities across participants (Polit & Beck, 2012).

Setting

A geographically defined area encompassing over 8,500 square miles in four counties located in 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 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 were 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. Veterans 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

This study was reviewed and approved by the university's Human Subjects Committee. Prior to the interview, each rural veteran received information about the study during the screening process and consent was documented. 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. Participants were not identified by name on the audio-recordings. Electronic data were encrypted, password protected, and stored in a locked file cabinet with the consents. Gift cards worth \$10 were 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. 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 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)

M (SD)

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 study area 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. Questions asked of all veterans included: How would you define palliative care, or what is your personal definition of palliative care; where is palliative care delivered; and when is the most appropriate time for palliative care. Additional questions were asked based on the individual responses of each participant. 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 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, with 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 by the primary researcher 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, and memos and reflective journaling were also used. Exemplar quotes provided 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 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 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 McIlpatrick et al. (2014) and Golla et al. (2014), the lack of understanding about palliative care was found among these rural veterans. However, no previous literature that we are aware of accounts for the fact that five of the veterans who participated in this study were familiar with hospice yet did not associate palliative care with hospice or specialized cancer care, such as reported by Golla and colleagues (2014); or end-of-life care, such as reported by McIlpatrick and colleagues (2014).

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). Similar to Golla and colleagues (2014), a

definition of palliative care was not provided to the rural veterans who participated 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 did these rural veterans (1) have no idea what palliative care is, and (2) why did five of the six rural veterans not perceive palliative care to be, in part, hospice care or end-of-life care?

In the region where this study was conducted, few palliative care programs exist. Hospice services are available in several of the small towns; however, hospice and home care services were not available in the areas where four of the six veteran participants live. The closest VA Medical Center with palliative care services was located more than 100 miles from where the six veterans live and does not provide home-based palliative care services in the veterans' area.

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 the communities or regions where they live, and facilitating access to concurrent palliative care throughout rural areas.

Suggested future research should focus on the preparation of professional caregivers and family members in the concept of concurrent palliative care for improving quality of life and exploring implementation 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 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.

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