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## Differences in Hospice Care Between Veterans and Non-Veterans

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## Differences in Hospice Care Between Veterans and Non-Veterans

By  
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MSW Clinical Research Paper

Presented to the Faculty of the  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
in Partial fulfillment of the requirements for the Degree of  
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

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### **Abstract**

The differences in hospice care needs between United States veterans and non-veterans was explored using a systematic review research methodology that consisted of 18 articles. After a review of previous research studies, it was found that veterans tended to want their healthcare providers to be more open and to the point about their diagnosis than non-veterans did. Both non-veterans and veterans wanted to be in control of their end of life cares. Non-veterans were more likely to want their family and friends around compared to veterans who were less likely to want people around. Veterans who had post-traumatic stress disorder (PTSD) received a lower quality of care compared to hospice patients who did not have PTSD. Patients who received a palliative care consult reported having less discomfort compared to those who did not receive a palliative care consult. Patients who received extra services such as Reiki or music therapy or caregiver support had an increase in peacefulness and a decrease in pain. With the additional caregiver support, patients were able to stay at home longer or until their death. This study shows that there is not a lot of research done around hospice care with veterans, but it is a unique group that needs to be focused on more in order to increase the quality of care they receive.

Keywords: hospice, civilians, veterans, military, palliative care, end-of-life, symptom management, comfort care

### Differences in Hospice Care Between Veterans and Non-Veterans

A misunderstood issue is hospice care needs with veterans and non-veterans. A lot is known about hospice care, but there is little known about hospice care with veterans specifically. The hospice model was first brought to the United States in the 1970's from the United Kingdom by Dr. Cicely Saunders and has continued to grow (Connor, 2007). According to the researchers, hospice is the number one used Medicare benefit today. Hospice is widely used within the non-veteran community and it has been shown to be effective in helping the patient and family members of the patient better cope with the end of life process. Hospice care is also used to make sure that the patient has the best end of life care possible, including as pain free process as it can be. If the gap between the use of hospice care by non-veterans and the use of hospice care by veterans can be bridged, hospice may become more widely used by veterans. Comparing the two populations may shed light on what is so different between the two populations and what needs to be done to increase the number of veterans choosing to use hospice care.

When an individual dies, many people are affected. The patient's family has lost a loved one and there are friends of the deceased and of the family who are suffering. Hospice care services can help those grieving before and after the loss of the patient as well as decrease the pain the patient may be suffering at the end of life as a result of their condition. According to Wachterman, Lipsitz, Simo, Lorenz, and Keating (2013) about 1.58 million people of the total population used hospice care services in 2010. There are a total of 642,000 U.S. military veterans who die each year (Wachterman et al., 2013). The area of concern is that out of the 642,000 U.S. military veterans who die each year, only about 5% of them received hospice care

compared to 21.6% of individuals who were non-veterans and on Medicare in 2000 (Wachterman et al., 2013).

If further research is done on hospice with veterans, there may be an increase in the number of veterans receiving hospice care. This would benefit not only the veterans, but their families as well. Veterans do not always want to go through the Department of Veterans Affairs (VA) to receive care so they may not be receiving the services they need. If people know what veterans want in their end of life process, they will be able to better receive the services they need outside of the VA. Hospice may help ease the pain of the patient who is dying and help with the grief process for the loved ones the patient has left behind. Another reason this is important to study is that hospice care is a growing field and everyone involved in the field of hospice needs to know how they can help. Increasing education about hospice may help with this. Staff can help educate the patients and their families to more effectively serve their patients.

A systematic review of current research on the topic is being done because little to no in-depth research has been conducted regarding the relationship between veterans and non-veterans in regards to the hospice care they receive and how they choose to use hospice. The current review will look at the patterns of use of hospice care by both veterans and non-veterans to help determine why there is such a large gap in numbers between the two populations and their use of the hospice care system. This would impact social work practice since social workers play a big role in the hospice care setting. Social workers have many visits with the patients to see how they are doing, give support to both the patient and their family, and provide the patient and family with the resources they need. When the social workers visit with the patients who are in hospice, they need to know how to approach them and what kind of services they want or like. It

is possible that this varies greatly among patients, but even more between veteran and non-veteran patients. It may be important to look at the causes of the differences such as, are the differences in needs because of the patient's military experience, the war era they served in, or if they have faced death before. With more research, social workers will be able to better understand what veterans want in their end of life process. This will help provide a positive experience and potentially increase the number of veterans who choose to use hospice care for their end of life process.

Some of the past literature that has been reviewed has tried to identify reasons as to why veterans have chosen not to use hospice care services at the end of their life. One explanation Wachterman et al. (2013) found was that it conflicts with the veteran's sense of pride. They may not want to admit that they need help or they see it as being weak. According to Edes, Shreve, and Casarett (2007), another possible reason that veterans may not be choosing to use hospice care services is because of the VA. A lack of hospice care service options, to some people, may be seen as a barrier to receiving services. The VA does not have options for veterans to receive hospice care in their home. However, the VA does provide options and referrals for hospice care providers that are in the community. With further research on the topic, it may be possible to increase the options or better the care for veterans who want to receive hospice care whether inpatient or outpatient. Some of the past research has done this through interviews with veterans and/or their family to gain a better understanding of what they want in their end of life care.

There are different reasons why a person decides to use hospice at the end of his/her life. When hospice first began, the patients who were enrolled in hospice had a primary diagnosis of cancer, but in 2010, only 35.6% of hospice care enrollees had a primary diagnosis of cancer

(Wachterman et al., 2013). The researchers found that more veterans than non-veterans who entered into hospice did so with a primary diagnosis of cancer. It is important to note that this study only used two groups for diagnosis, cancer and non-cancer. However, the study broke down the non-cancer category so that they could look at comorbid disorders. The most common non-cancer diagnosis for both veterans and non-veterans was dementia.

As a result of the few veterans who chose hospice care, the VA took the initiative to increase that number by creating programs and partnerships throughout the United States. These programs were funded through the VA and resulted in a three-fold increase between 2006 and 2009 (Wachterman et al., 2013). Veterans and non-veterans were both most likely to have their hospice care paid for by Medicare. Veterans were also likely to have the VA pay for their hospice care. Non-veterans were more likely than veterans to have Medicaid or private insurance pay than veterans were.

Alici et al. (2010) conducted a study using veteran patients' family members to assess post-traumatic stress disorder (PTSD) symptoms at the end of the patients' lives. One finding of the study was that if the family reported the patient having PTSD symptoms, their experience of care at the VA was poorer than those patients who were not showing signs or symptoms of PTSD. Family members who said the patient showed symptoms of PTSD at the end of life were more likely to report lower satisfaction with communication from the caregivers and less emotional support. It was reported that patients who had pain were more likely to have symptoms of PTSD. When looking at the level of comfort the patient experiencing, the patient's PTSD symptoms made them more uncomfortable than dyspnea, but pain caused more discomfort for the patient than their PTSD symptoms did. Is it possible that the number of deployments the patient experienced influences the severity of their PTSD symptoms? It is worth noting that

older veterans did not use the term PTSD, but rather they used combat stress as a term to describe what we today call PTSD.

After reviewing previous literature, the question that stands is “what are the unique needs of veteran hospice patients as compared with non-veteran hospice patients?”

### **Conceptual Framework**

The framework that fits this study the best based on the sample and question is the humanistic perspective. Humanistic perspective is, “an approach that sees human behavior as based on freedom of action of the individual and focuses on the human search for meaning” (Hutchinson, 2011, p. 532). It is composed of humanistic psychology, existential psychology, and transpersonal theory. Morrissey (2011) explains that the humanistic perspective “is elaborated for understanding agency, obligation, and ethical choice in end-of-life decision making” (p. 15). This framework is appropriate for this study because hospice patients are able to make their own choices as long as they are cognitively able to. The humanistic perspective references the idea that all individuals have value and are unique in their own way (Hutchinson, 2011). Hospice focuses on the value and worth of a person at the end of their life as well as their past experiences that have given their life value. It also refers to individuals having the ability to make their own choices. The humanistic perspective is about individuals having the ability to make their own choices.

In general, hospice is about making sure the patient is comfortable during their end-of-life process. The humanistic approach focuses on the person as a whole and their unique needs, values, and ability to change. It has been used with this target population for this reason. This framework has been used in the past as a part of social work to ethically help the older vulnerable adult population through their end-of-life process (Morrissey, 2011). There are not a

lot of studies available to show how this perspective has been used with this population, but there is information that supports the usefulness of this perspective with hospice patients. Based off of this information the humanistic perspective was chosen for this study.

I am drawn to this framework because it focuses on the whole person and puts their wishes and needs first. This is very important in the social work field. I am approaching this topic in a person-centered way. The humanistic perspective says that the social worker needs to know what the client knows about their situation and how they feel about it (Hutchinson, 2011). Hutchinson (2011) also notes that pointing out the client's strengths is important and helps them grow in whatever way they want or are able to. Social work and hospice care place value on meeting the client where they are at. Hospice care social workers become aware of how they are supposed to approach the topic of hospice to the patient. They meet the client where they are at in terms of their understanding of what hospice is and the amount of information they want to know. Another bias I hold is that I choose to point out the strengths in the clients and do life review with them to point out all that they have accomplished throughout their life. This helps give their life worth and point out their strengths as which is important.

To guide in gathering information, the focus of the research will be on the individual needs of each patient. This will help to better understand how veterans and non-veterans have unique needs and wishes at the end of their lives. When gathering information, attention will be put on how studies have used the humanistic perspective in some way. The studies may not have referenced the perspective directly, but use the ideas of the perspective.

### **Methods**

The design for the current study is a systematic review of previous research that has been done related to the topic of hospice care with military veterans and non-veterans. Palliative care

and hospice care are frequently used interchangeably so articles relating to palliative care were also used when they fit the other article search criteria. A systematic review is used when a topic has not been thoroughly looked at or studied. Current research articles related to the topic are synthesized to find common themes. In a systematic review, articles that are found are assessed for quality to ensure that the best articles are being used to sum up the current research on the topic. There is enough research on hospice care in the United States so the research was limited to only those done in the U.S.

### **Inclusion Criteria**

The inclusion criteria for research articles permitted flexibility on the design of the studies that were used for the current study because of the limited amount of research available and the many different approaches that have been used.

The articles' abstracts were reviewed prior to reading the article to be more efficient when looking for articles. If the abstract did not seem to have the information I was looking for, I did not further look at the article.

A systematic literature review is a type of research that is used to further study a topic that has not been thoroughly studied or shows gaps in the research. Systematic reviews are useful to help organize the previous research and identify where the gaps in the research are. Below is a description of limiters and other search criteria that were used to gather prior research. Some of the search criteria include the time frame that will be used, the designs of the studies, the sample, search databases, search terms, and how the articles will be organized. The articles were assessed based on their methods, themes, and sample.

The topic of the current study is hospice care needs for veterans and non-veterans. More specifically, how the needs of care differ between veterans and non-veterans. In order to make

sure the most recent data was being used, the time frame of the previous research ranged from 2004 to 2014. The design of the study was flexible because there has not been a lot of research done on this topic in the past. The sample includes United States veterans and non-veterans who have received hospice care or are receiving hospice care. Only research studies that were completed in the United States were used because there were enough studies found without having to expand to use research studies from other countries.

### **Search Strategy**

Certain search strategies were used to gather the most relevant research studies. The data bases that were used to find the studies were PsychINFO, Social Work Abstracts, SocINDEX, and MEDLINE. Within those databases, the following keywords were used to search for articles related to the current study, hospice, civilians, veterans, military, palliative care, end-of-life, symptom management, and comfort care. In order to limit the results of the searches the following limiters were used, only articles that had a PDF full text, articles that were peer reviewed journal articles, and articles that had references available.

In order to track the articles, a template was used to track the articles that I found, the articles that were used, and why articles were excluded.

### **Data Collection**

A grid was designed to help organize all of the articles used in this study. The grid included the title/author/date of the article, topic, design, sample, measures, and findings. Once all of the data was collected, the grid was filled out to better lay out all of the information. Themes were identified based on what the findings from the other research studies showed.

After all of the articles were found and deemed appropriate for the study they were further looked at in order to abstract the appropriate data and findings that would be important to the

current study. For this particular study it was important to find common themes across previous research articles that were completed relating to veterans and non-veterans and their hospice care needs. Some of the information that I pulled out of the articles pertained to the hospice patients' wishes and goals. One of the main goals of hospice is to meet the patient's wishes so this was an important thing to focus on. Based on the similarities that were found among the articles, themes were identified in order to better organize the information and understand it. From the 18 articles that I used I abstracted information relating to the sample of participants, the size of the sample, and if there was a comparison group used or not. The articles that I used needed to be focused around the cares the patients were receiving and not about perceptions social workers or family members held. Information about the comparison groups was abstracted from the research articles. Articles that compared demographic differences were excluded from this research study because those comparisons were irrelevant to the current study. Figure 1 on the next page shows how I tracked the articles that I found and why I chose the articles I did.

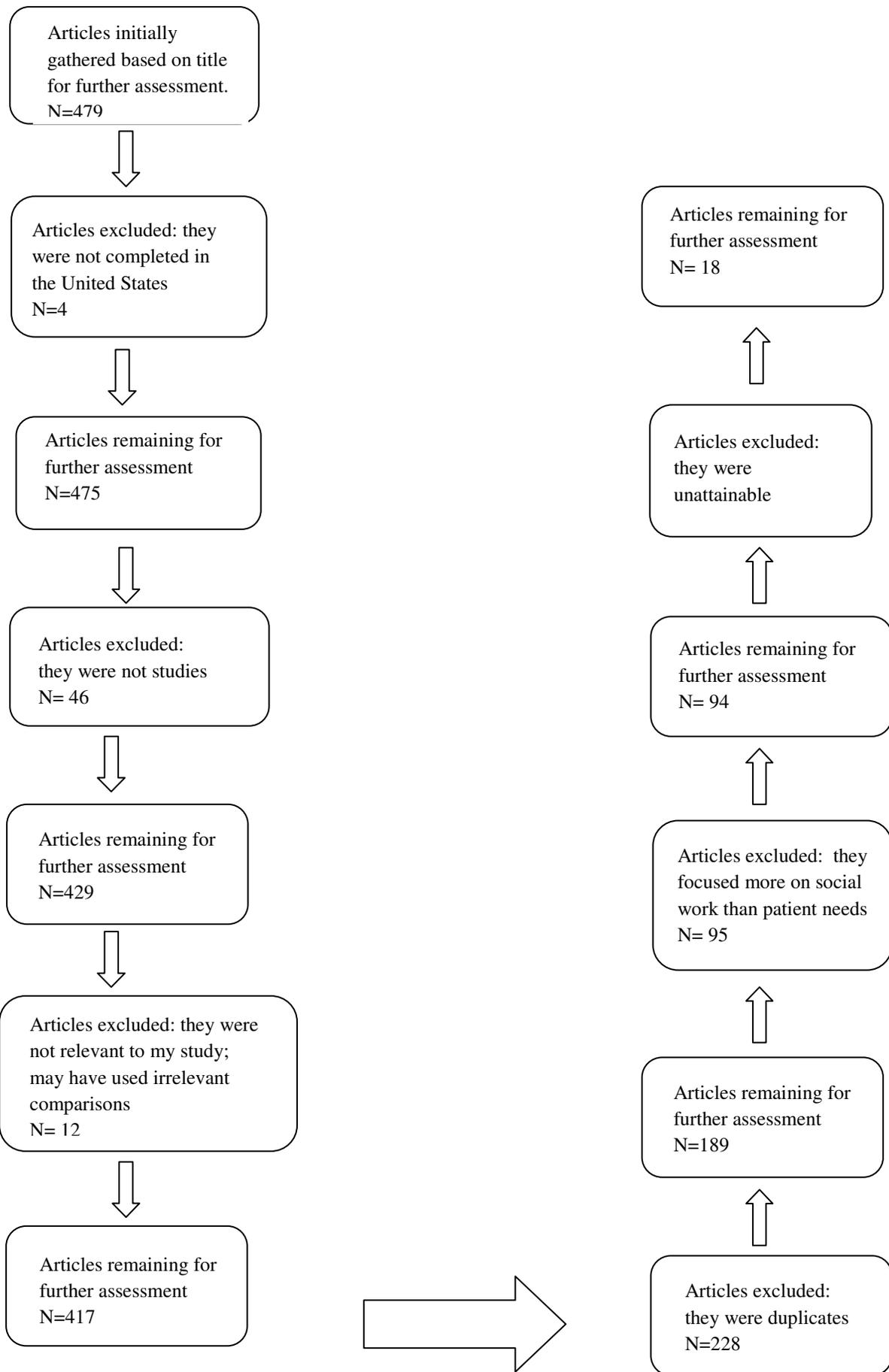


Figure 1: Process of choosing appropriate articles for study

## Analysis

As I searched for articles, I started by looking at the titles and abstracts of the articles I found to see if they were relevant to the current study. If they seemed relevant based off of their title and abstract, they were downloaded and recorded as my starting articles. I then further assessed the articles by looking at them more in depth to assess their quality and to make sure they were still relevant. The number of articles that were kept after further reviewing the articles and the number of articles that were thrown out were tracked. One reason that articles were thrown out was that they were not an empirical study. If the article was not relevant to the topic after it was further reviewed, it was thrown out. Based on the findings of the articles, themes and subcategories were determined.

Table 1. Process of Assigning a Quality Rating Score to Research Articles

Method	Quality		
	1 (poor)	2 (moderate)	3 (high)
Sample Size	<150	151-800	>801
Participants	Social workers	Family members and caregivers	Veterans and non-veterans
Comparison	None	Veterans and veterans or non-veterans and non-veterans	Veterans and non-veterans

The articles were assessed using a numerical system based on the quality of its methods (table 1). If an article was deemed poor, it was given a '1', a moderate quality score was given a '2', and high quality was given a '3'. In order to give the article a numerical value, there were certain qualities that were assessed. A method of the study that was assessed was the sample of the study. This was assessed based on the size of the sample. If the sample size consisted of less than 150 participants, the sample size was given a '1'. The sample size was given a '2' if it was between 151 and 800. All studies that had more than 800 participants were given a '3'. This was based on the ability of the researchers to gather an effective amount of participants for a

study to be effective. The larger the sample size is, the more data there is to support the research study and its findings. Another method to analyze was the participants of the study. Was the participant a family member of the patient, a caregiver, or the patient? Participants, who were a veteran or non-veteran, would have firsthand knowledge and experience about their cares and thus the rating score would be higher. The quality decreased as the information was gathered from participants who were farther away from the patient in terms of knowing the patient and their experiences. If the participants were social workers, the quality of the participants were given a '1'. When family members and caregivers were used as participants the quality of the participants was given a '2'. The quality of the participants was given a '3' if they were veterans or non-veterans. Whether or not a comparison group was used was assessed as well. If a comparison group was not used, it was given a '1'. If the comparison group was between veterans and other veterans or nonveterans and other nonveterans, it was given a '2'. The comparison quality was given a '3' if the study compared veterans with nonveterans. The studies that had a comparison group were given a higher quality score because the data was able to be compared to something to check the effectiveness of an intervention. If there is not a comparison group, it makes it harder to determine whether or not the change would have occurred anyway without the intervention. Once each category was given a quality score, the numbers were added to give the study an overall quality score.

### **Findings**

After a thorough search of the research that has been done relating to hospice care among veterans and non-veterans, a total of 18 studies were deemed appropriate for this systematic review of the literature. From those 18 articles, the following themes emerged:

- What the participants' end of life (EOL) goals and wishes were

- The amount of family involvement and support a patient wants and the effects of it
- The quality of care and satisfaction the participants received from their providers and their caregivers
- Services participants wanted or used as a part of their hospice care

Refer to table 2 on the next page to see a more laid out view of the articles. This figure shows what themes each article fit into, the overall quality of the article based on the quality table shown above, who the participants were, the size of the sample, and if there was a comparison group used or not.

Table 2: Brief Summary of Articles Based on Themes and Quality Assessment Factors

Theme	Total quality score out of 9	Author (year)	Participants	N	Comparison Group
End of life goals and Desires Family involvement and support Services	8	Sudore, Casarett, Smith, Richardson, and Ersek (2014)	Veteran descendants	34,290	Yes
End of life goals and Desires Family involvement and support Quality of care and satisfaction	5	Kumar, Markert, and Patel (2011)	Veterans and their family	26 for the first survey 18 for the second survey	No
Services	6	Gonslaves et al. (2011)	Veterans	200	Yes
End of life goals and desires	5	Rodriguez and Young (2005)	Veterans	30	No
Quality of care and satisfaction Services	7	Alici et al. (2010)	Veterans and their families	524	Yes
Quality of care and satisfaction	6	Casarett et al. (2008b)	Veterans' family members	66	Yes
Services	7	Casarett et al. (2008a)	Veterans' family members	524	Yes
Family involvement and support Services	5	Nelson-Becker (2006)	Non-veterans	30	No
End of life goals and desires	5	Vandergrift (2013)	Non-veterans	52	No
End of life goals and desires	5	Waldrop and Meeker (2012)	Non-veterans and their caregivers	36 non-veterans 55 Caregivers	No
End of life goals and desires	5	Schroepfer, Noh, and Kavanaugh (2009)	Non-veterans	84	No
Family involvement and support	5	Neimeyer, Currier, Coleman, Tomer, and Samuel (2011)	Non-veterans	153	No
Quality of care and satisfaction	8	Bischoff, Sudore, Miao, Boscardin, and Smith (2013)	Non-veterans	4,394	Yes
Family involvement and support Ethical dilemmas Services	3	Csikai (2004)	Social workers	110	No
Services	9	Empeño, Raming, Irwin, Nelesen, and Lloyed (2013)	Caregivers of non-veterans	182	No
Services	8	Miller, Lima, and Mitchell (2012)	Non-veteran hospice enrollees and non-hospice enrollees	4,344	Yes
Services	9	Wachterman, Lipsitz, Simon, Lorenz, and Keating (2013)	Veterans and Non-veterans	483 Veterans 932 Non-veterans	Yes
End of life goals and desires	7	Duffy, Ronis, Fowler, Schim, and Jackson (2006)	Veterans and Non-veterans	15 Veterans 47 Non-veterans	Yes

## Themes

### **Participants' end of life goals and desires for end of life care plan.**

Five studies identified participants' EOL goals and wishes. Goals and wishes were found to vary depending on whether or not the participant was a veteran or non-veteran. Two out of the five studies focused on end of life goals (Duffy, Ronis, Fowler, Schim, & Jackson, 2006; Rodriguez & Young, 2005). Three of the five studies explored patient's desires for their EOL care plan (Kumar, Markert, & Patel, 2011; Schroepfer, Noh & Kavanaugh, 2009; Waldrop & Meeker, 2012).

### ***Participants' end of life goals.***

The two studies that fit under this subtheme were rather strong articles as they had a combined average quality rating of 6%. At one point or another, both studies used some sort of a survey method to obtain information from the patients regarding their EOL goals. Their main limitation was that they both had a small sample size. Rodriguez and Young (2005) completed a study looking at the perspectives of veterans and what they want from their medical providers at EOL. This was a cross-sectional survey that used qualitative content analysis. The researchers found that most of the veterans wanted somebody who was compassionate to be at their bedside with them. Making sure that the medical provider knew their patient's information and what their healthcare preferences were, were not as important to the veterans, but still a noteworthy finding of the study. Other findings from the study included veterans wanting a medical provider who made sure that they, as a patient, understood what was going on with their healthcare. It was evenly distributed between veterans that they wanted their medical provider to be open, honest, and truthful with them, a provider who provided empathetic care, someone who took the time needed to give them the appropriate cares they needed, and a provider who was able to

know the important information about the patient and their EOL wishes and preferences. This study did not compare veterans to non-veterans specifically, but a study by Duffy et al. (2006) looked at some of these same EOL wishes in their pilot study comparing veterans and non-veterans.

Ten focus groups were used in their pilot study and a discussion guide for the researcher to use. When comparing veterans and non-veterans, Duffy et al. (2006) found that veterans tend to be less connected to their culture, racial, and ethnic group than non-veterans. Similar to Rodriguez and Young (2005), Duffy et al. (2006) found that veterans are more likely than non-veterans to want their doctors to be open and frank with them. Veterans were more likely to want a do not resuscitate (DNR) order. An interesting finding is that veterans did not want to remember personal accomplishments or want to be around their friends, but they were more likely to want to have their pets with them. Two veterans, who were in active duty combat zones, noted in the survey that this experience changed their EOL wishes and choices. No differences were found in terms of the specific treatments the two groups chose, whether they wanted to die at home or somewhere else, their views on assisted suicide, or the way in which they viewed or dealt with having a threatening illness. Another similarity that was found among studies was the topic of how much control the participants had or wanted at EOL.

***Desires for end of life care plan.***

Two of these studies used interviews to gather information for the study (Schroepfer, Noh, & Kavanaugh, 2009; Waldrop & Meeker, 2012). The three articles had a combined average rating score of 5%, but again this was a result of the studies have a small sample size and also two of the studies, Schroepfer et al. (2009) and Waldrop and Meeker (2012), did not use a comparison group. A study conducted by Schroepfer et al. (2009) used 84 terminally ill elderly

non-veteran participants. This study used face-to-face interviews with a directed and conventional content analysis. Schroepfer et al. (2009) found that over 50% of the participants wished they could have had more control at EOL, but they thought that their illness was the primary limitation to having full control. All of the participants used one or more strategies that would help them gain as much control as possible at EOL. Most participants used a primary control strategy with a second primary control strategy or compensatory secondary control strategy. Similarly, a study conducted by Kumar et al. (2011) used two surveys; one at the beginning of the veteran's admission and a second survey was given out to be completed by caregivers or family members of the deceased veteran. This exploratory study measured goals at EOL by using a survey that had a Likert Scale. The initial survey found that 100% of participants wanted to have control of their symptoms at EOL and felt that they were able to have control (2011). In the second survey, 78% of the family members or caregivers agreed with control of EOL symptoms as an important goal for patients to have (2011). Probably one of the most important and noteworthy findings of this study was that when the patients' wishes were followed, they had an increase in satisfaction with their care.

Waldrop and Meeker (2012) found that at times non-veteran patients no longer wanted to seek treatment because it was inconvenient for them or it was just too much for them to continue to receive treatment. This was the patient's decision and their desires were followed despite this not being the wishes of majority of the patients used in the study. Another finding was that overall patients simply wanted to make sure that their needs would be met. This was important to nearly half of the patients in the study. Patients not only wanted support and help for themselves, but also for their family and caregiver. It was found that family members, as well as patients, had a difficult time when the patients lost control as their illness worsened. This was

similar to the finding from Kumar et al. (2011). This shows that the role of family can be different among different people and the amount of support one wishes to have varies.

### **Family involvement and support.**

Among the six studies that related to family involvement and support among hospice care, there were differences found between studies and participants. The overall average quality rating for these articles was 5.7%. As with other themes, this was a result of a small sample size among most articles. It was shown that participants who had more support from family and friends fared better health wise than their counterparts who did not have much support. Three of the studies used a cross-sectional method to conduct their study and had an average overall rating of 7% (Bischoff, Dusore, Miao, Boscardin, & Smith, 2013; Neimeyer, Currier, Coleman, Tomer, & Samuel, 2011; Sudore, Casarett, Smith, Richardson, & Ersek, 2014). In the study conducted by Kumar et al. (2011), used two surveys, one within 5 days of admission and the second was completed by family members because patients had died before the second survey was sent out. In the first survey, 100% of the patients who were veterans reported that they strongly agreed on being in control of their EOL symptoms, 92% agreed with having time for family, 73% wanted to return home and 54% of the veterans agreed with wanting help to gain peace through spirituality. In the second survey, the family members did agree more with the goal of allowing time for family, 100%, compared to 92% of the patients who agreed with having time for family and family members agreed with the patients being in control of the EOL symptoms 78% of the time (2011). In a study conducted by Sudore et al. (2014) compared what the EOL quality of care looked like depending on the involvement from the family with non-veteran patients. Results of this study showed that 94.2% of the veterans wanted their family involved in their

EOL cares (2014). Those who did not want as much family contact, tended to be younger veterans.

Two studies found that social support at EOL is important to the wellbeing of hospice patients. The average rating of these two studies combined was 5%. This is about middle quality for an article. The participants were all non-veterans which increased the quality, but the sample size for both articles was small. Neimeyer et al. (2011) conducted a study to determine what impacts various factors had on how much a hospice patient suffers at EOL. When the researchers assessed the patients' social support, it was found that those patients who had more social support, tended to suffer less at EOL, they were more able to accept death, and had less fear about death. Those who had more social support also worried less about future regret, what will happen after they die, and were overall better psychologically. Nelson-Becker (2006) found that patients described their family as a gift they were receiving and the support they received from them was important to them. The support they received helped make the EOL process less worrisome and eased the emotional pain they were having around the thought of their death. While the patients were appreciative of all the support they were receiving, they also worried about what life would be like for their loved ones after they died. This led to more economical worries than the void the family would have.

It is hard for family members to watch their loved ones suffer. The other studies have discussed the support a patient receives from family and friends at EOL, but a study conducted by Csikai (2004) looked at things in a different perspective. This study had a rating of three out of nine. Csikai's (2004) study looked at assisted suicide among non-veterans enrolled in hospice. Although the participants of this study were social workers which led to a lower quality score, the results are important. Social workers found that 32% of their patients brought up

assisted suicide and questioned if it could be done for them (2004). An interesting finding that was only mentioned in this study was that 17% of patient's family members explored assisted suicide as a possibility for their family member (2004). This was not done to hurry the process up, but rather to help end the suffering of their loved one. This can be seen as a positive support especially if the patient and family member are in agreement. Given this information, the article's overall rating was a three. There was no comparison group, the sample was small, and the participants were social workers.

Overall, it was found that family, friends, and support are important to patients despite whether or not they are a veteran or not. These factors can also determine how the patient accepts death and if they are comfortable at EOL.

#### **Quality of care and satisfaction.**

After going through all of the articles, 11 studies looked at the cares the patients' providers or caregivers administered, the quality of care they received, and the satisfaction they had with their cares.

Out of the 18 studies being used in this systematic review of the literature, three articles addressed the quality of care the hospice patients received at EOL. Two of the studies only used veterans as participants and had a comparison group (Alici et al., 2010; Casarett, Pickard, Bailey, Ritchie, Furman, Rosenfeld, Shreve, and Shea, 2008b). Having veterans as participants and using a comparison group improved the quality of the two articles, giving them an overall average quality rating score of 6.2%. Alici et al. (2010) used 524 hospice patients and their families focused on ways to identify how often PTSD symptoms emerged at EOL and how that affected the quality of care the patients received. They used telephone surveys to contact the family members of the patients. Alici et al. (2010) found that PTSD significantly affected

patients at EOL. It was determined that 17% of the patients experienced symptoms that resembled PTSD (2010). Pain caused more discomfort for the patient than PTSD did, but PTSD caused more discomfort than dyspnea did. If the patient had a palliative care consult, they tended to rate their level of discomfort lower than those who did not have a palliative care consult. Not all patients can report a high quality care. Casarett et al. (2008b) used family members as the participants to reflect back on the care their loved one, who was a veteran, received at EOL both in the VA system and outside of the VA system. The biggest complaint that related to the quality of care that the patients received was related to the difficulty of accessing VA services. Family members noted that facilities did not always listen to the food preferences of the patients and thus the patients would not eat their meals. The family members were concerned about the way their loved ones were handled, whether it was cautiously and safe or not. Another big concern was whether or not the veterans' PTSD symptoms were handled in an appropriate manner or if these symptoms were overlooked by the care providers. The quality of care that a patient receives does not always start and end with the caregivers and medical providers. Casarett et al.'s (2008b) study and a study done by Bischoff et al. (2013) were cross-sectional studies. The main focus of Bischoff et al.'s (2013) study was how a patient having an advance care plan (ACP) in place affected their quality of care at EOL. Overall it was found that if a patient had an ACP in place, their overall quality of care at EOL was greater. The patients with an ACP had a decrease in hospital deaths, 92% wanted only comfort cares, 5% wanted limited cares, and 3% wanted all cares (2013). The quality of care a patient receives can also be directly related to how satisfied they are with their cares. When we think about quality of care, satisfaction emerges and there were two articles that explored the patients' overall satisfaction in their care.

Alici et al. (2010) looked at not only the quality of care, but also the overall satisfaction of the patients' care. The overall finding in terms of satisfaction of care related to PTSD. Families of the patients reported that if their loved one had PTSD, they were far less satisfied with the cares than those patients who did not have PTSD. There were reports that were made from the patients' family members that if the patient had PTSD less social and emotional support was given to the patient at EOL. The care provided to patients with PTSD was not as good, the care providers seemed to spend less time with the patients who had PTSD and were not given as much attention. As mentioned above, the study conducted by Kumar et al. (2011) found that if the patients' EOL wishes were followed and met, they had a greater satisfaction with their EOL cares. Alici et al.'s (2010) article had a cumulative rating of seven out of nine and Kumar et al.'s (2011) article had an overall cumulative rating score of a five out of nine. The main difference between the overall rating scores was the difference in sample size. Alici et al. (2010) had a much larger sample size, but Kumar et al. (2011) used both veterans and their families which may have increased the validity of the results having two perspectives.

### **Services.**

One of the focuses of some of the articles was on palliative care consults. Four of the 18 articles related to veterans and their EOL quality depending on whether or not they had a palliative care consult. Included in this theme there were four articles that looked at the services utilized by hospice patients.

#### ***Palliative care consult.***

Both Alici et al. (2010) and Casarett, Pickard, Bailey, Ritchie, Furman, Rosenfeld, Shreve, Chen, and Shea (2008a) assessed the use and effectiveness of palliative care consults using comparison groups, used patient's family as part of their sample, and had an overall

average quality rating score of 7%. Their overall quality rating was high as a result of them using veterans as their participants and both using a comparison group. Alici et al.'s (2010) main finding was that veteran patients who received a palliative care consult reported having less discomfort compared to those who did not receive a palliative care consult. Casarett et al. (2008a) compared palliative care to usual care and the outcomes the patients experienced with their cares. This study used a retrospective approach as well as a study by Gonslaves et al. (2011). The overall findings from Gonslaves et al. (2011) showed that having a palliative care consult improved the patient's, who were veterans, quality of EOL cares. Patients who had cancer, some confusion, and a prior hospital stay were more likely to accept a palliative care consult. Those who did not have a consult were more likely to not want any type of emotional support. The earlier the consult was done, the more communication and emotional support the patients wanted. In Gonslaves et al.'s (2011) comparative study, the participants formed two categories, one that consisted of patients from 2002 and one that had patients from 2008. It is important to note that the two years were chosen based on when palliative care services were introduced. When PCS were used, there was an earlier referral and enrollment into hospice. When the researchers looked at the sample from 2008 compared to 2002, those from 2008 who had a PCS consult, were less likely to receive chemotherapy treatments, go to the emergency department for cares, have one or more admission to the hospital or spend 14 or more days in the hospital, and were less likely to be admitted to the intensive care unit.

The study done by Sudore et al. (2014) that was mentioned above also looked at the effectiveness of palliative care consults. Although this shared the same theme with the other articles, it did not share a lot of similarities between the others, but is important as it had a quality score of eight out of a possible nine. In relation to the amount of family involvement,

those veterans who had a high involvement with family, were more likely to have a palliative care consult than those who did not have a lot of family involvement in their cares. Patients were more likely to die in a facility or unit that had palliative or hospice care when there was greater family involvement. Patients also had an increase in chaplain visits when they had a palliative care consult and have a DNR order.

***Additional services.***

Certain additional services were mentioned in a couple of studies that may help improve the cares patients receive while in hospice. Those services include different types of therapies for patients as well as supportive services for the patient's caregiver. Vandergrift (2013) completed a study that identified additional services that were utilized by hospice patients. This study focused on how the implementation of different types of therapy would affect the EOL quality of care. The findings showed that introducing different therapies such as Reiki therapy and music therapy had a positive impact on the patients' comfort at EOL. The major findings showed that 99% of patients reported a decrease in stress and anxiety, 92% reported that after receiving one of the therapies they were able to breathe easier, 76% had a decrease in their pain, and 92% were able to become very relaxed and expressed an increased level of peacefulness (2013). One service that was offered that was indirectly related to the hospice patients was that of increased support to the caregiver. Vandergrift (2013) found that incorporating therapy into hospice cares can decrease the stress the patients experience. Empeño, Ramine, Irwin, Nelesen, and Loyd (2013) assessed the impact of additional caregiver support as a way to decrease the stress that the patient's caregiver experiences. The idea of this study was to assess the effectiveness of caregiver support to decrease the rate of burnout. Caregiver support was done by having someone come take care of the patient temporarily so that the caregiver could get out

of the house for a bit, run errands, have help with housekeeping, or have help with transportation of the patient and their caregiver. The findings showed that having implementation of caregiver support decreased the amount of stress the caregiver experienced. This is related to the patients in that when the caregivers had less stress, it was easier to keep the patient at home longer or even until their death.

Studies done by Miller, Lima, and Mitchell (2012) and by Watchterman et al. (2014) both used a comparison group in order to study the specific needs and differences among hospice patients. Both studies were of high quality with a combined cumulative rating score of 8.5%. Miller et al. (2012) looked at the difference in hospice care when patients were in a skilled nursing facility (SNF) among hospice enrollees and non-hospice enrollees. The findings of this study were that those patients who were enrolled in hospice were more likely to have a DNR order, but an increase in pain. Hospice showed to have fewer deaths that occurred in a hospital. Patients enrolled in hospice took fewer medications and were less likely to have a feeding tube, or any intravenous fluids given to them. Wachterman et al. (2013) compared veterans and non-veterans. The study found that veterans who used hospice tended to be older than non-veterans and were more likely to have a primary diagnosis of cancer, 56.4% compared to 42.4% (2013). Veterans were also more likely to receive hospice care in their home compared to any other setting, 68.4% compared to 57.6% (2013). Most interesting was that veterans did not receive home health aide visits as the non-veterans did. The researchers believed that this was due to the fact that veterans did not have as much of a decline in their mobility. They believe that it could also be a result of the veteran having too much pride and them not thinking they need assistance.

## Discussion

The research study was a systematic review of previous research done on the topic of hospice care among veterans and non-veterans. There were four main themes established based on the information found in the 18 articles that were used in this study. Although the themes covered different areas of hospice care, the overall message was that hospice care and palliative care services have more of a positive impact on the quality of care patients experience at EOL. It is important to further explore the unique hospice care needs of veterans because of the growing veteran population. The Korean and Vietnam veterans are getting older and they would be able to benefit from hospice care services if they are able to have their unique needs met. One noteworthy finding from this research is that there is not a lot of research that has been done comparing both veterans and non-veterans. This study is able to shed light on social work practice, research practice, and even social work policies.

There was only one article that related to ethical dilemmas, but it seemed noteworthy for the study and is an important part of social work. Ethical dilemmas often arise when working in EOL care. A study by Csikai (2004) used 110 social workers as their participants to assess ethical dilemmas that arise in EOL care and how to resolve them. Out of the 110 social workers who participated in this study, 91% of them were female and 91% were Caucasian (2004). This was an exploratory study that used a questionnaire that had a Likert Scale. The findings showed that 32% of the social worker participants had a patient ask about assisted suicide (2004). Interestingly enough, 17% of the 110 social workers asked, had a patient's family member ask them about assisted suicide (2004). The social workers, who were older, had a more difficult time talking about ethical dilemmas that arose in their work. Although the patients were not the

primary participants in this study and the overall quality of the study was a three, it seemed important to note how a family member does not always want to prolong the life of a loved one.

### **Practice implications**

The findings that were reviewed have some implications for social work practice. It is important as a social worker who is working with hospice and palliative care patients to make sure that the patients' needs are being met and that they are receiving the care necessary to their diagnosis. Certain diagnoses may be overlooked or avoided such as PTSD. Ethical dilemmas will also arise when working with the patients. It is important to advocate for the patients. The social worker should have the patients' best interest in mind even if it goes against the social worker's morals or values. Adding in other services such as complimentary therapies to the patients' care may improve the quality of the patients' EOL symptoms. The social workers working with those patients can help set up the services for the patients.

### **Research practice**

Further research needs to be done to further assess the differences between veterans and non-veterans and their hospice care needs. This systematic review used a total of 18 articles and that was limited. Only two articles directly compared veterans and non-veterans, but those two articles were of high quality. One article was rated a nine and the other was rated a seven out of nine on the quality scale. The overall quality rating of all 18 articles was 6.3% which shows that the articles were of fairly high quality. There was limited research found that was related to the current study which means that a lot more research needs to be done in order to fully understand the unique needs of veterans. It was found that hospice patients who are veterans with PTSD have a lower level in hospice care satisfaction because their unique needs are not being met. Veterans continue to get older and we need to be able to care for them appropriately. As one

study found, part of the reason veterans do not utilize hospice services is because of their pride. Being able to know more about veterans' pride and how to work through that with them could lead veterans to better utilize the services that hospice offers and enroll in hospice.

Future research on this topic could focus on regional differences. Being able to compare regional differences may help improve hospice care services for veterans. If it is found that one region of the United States has better hospice care services for veterans than those techniques may be able to be replicated in other regions.

### **Social work policy**

After gathering research that explains different hospice needs among veterans and non-veterans, there are ways in which changes or improvements can be made to better meet the needs of veteran hospice patients. One finding was that veterans want their healthcare providers to be open and honest with them whereas their non-veteran counterparts would prefer their healthcare providers to not be fully honest with them. This is something that can be easily modified. Healthcare agencies will need to make it known that when a veteran is on hospice, the healthcare providers may need to alter their approach a bit in order to meet the specific needs of veterans. Education may help with this as well as other policy implementations.

It was found that veterans are more likely to want a DNR order compared to non-veterans. This may be for a variety of different reasons. This is a personal preference and there is not right or wrong choice. The important thing is that the patients are able to make an educated decision. It may also be important to look more into this difference among the two groups. Would more education around the topic of DNR orders change a patient's wishes?

In summary, there were only a few similarities found between hospice care wants and needs between veterans and non-veterans. As Wachterman et al. (2013) noted, veterans may

have too much pride to ask for help or they may not see their mobility limitation as bad as it really is. One similarity that was found was that for some veterans, they want their family members present as much as non-veterans do. Another take home finding is that in all patients, hospice and palliative care services positively affect almost all patients. Patients want to be in control of their cares and their families want to be there to support them and advocate for their loved ones to be sure that they receive the appropriate cares. It is also important to patients across both subgroups that they are informed about their cares and they want to receive cares from caregivers who take the appropriate time needed to care for them.

Vietnam and Korean War veterans are entering their later years of life and would likely benefit greatly from using hospice. A lot of veterans have PTSD as a result of their time being in the military. When it is discovered that veterans receive less attention because of their PTSD, it raises a red flag. Is this due to a lack of education/awareness? If so, more education should be done to better help our veterans receive the best care available.

### **Strengths.**

Some studies had participants that were both hospice enrollees and their family members. This appears to be a strength of the studies because one was able to not only get the perspective of the patient, but the family member as well. Perceptions vary among people, but even more greatly among patients and their families.

There was an article that discussed PTSD and how it relates to the cares the hospice patients who are veterans receives. This demonstrated an important finding and shed light on a growing concern when working with the veteran population. This showed one of the biggest unique needs that veterans who are receiving hospice care need.

When comparing research it helps when authors are part of multiple studies and are building off of their previous research. The author Casarett was a part of three different research articles that were used in this current study. He has done research and is able to apply his knowledge to other areas.

### **Limitations**

The overall limitation of the articles that perhaps lowered the overall quality rating was that most of the articles did not compare veterans and non-veterans. With hospice care growing it is hopeful that more research can be done. This will hopefully help determine why veterans do not use hospice care as much as non-veterans.

One way to improve the quality of future studies is to increase the sample size. The overall quality of the studies based on sample size was 1.5%. Majority of the studies had a sample size that was less than 800. This did not necessarily mean that the overall quality of the study was low, but it does show some concern based on lack of participants and information gathered. Only two of the 18 articles had an overall high quality rating with a nine out nine rating. Only half of the articles used a comparison group and therefore the research was unable to be compared to a control group showing that the results of the intervention were effective.

This systematic review of the literature only reviewed 18 articles out of 479 that were originally reviewed, but for various reasons rejected. Having more research on this topic would have increased the quality of this study because there would have been more data to compare. This was another important limitation to consider when looking at this study.

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